Evaluation of a Novel Cardiopulmonary Resuscitation (CPR) Video Decision aid to Promote Shared Decision-making with Nephrology Patients and Families

A Thesis Submitted to the College of Graduate and Postdoctoral Studies
In Partial Fulfillment of the Requirements
For the Degree of Master of Nursing
In the Department of College of Nursing
University of Saskatchewan
Saskatoon

Submitted By
Cherie E. Kapell Brown

PERMISSION TO USE

In presenting this thesis in partial fulfillment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professors who supervised my thesis work or, in their absence, by the Head of the Department or the Dean of the College in which my thesis work was done. It is understood that any copying or publication, or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis.

Requests for permission to copy or to make other uses of materials in this thesis/dissertation in whole or part should be addressed to:

Dean of the College of Nursing
University of Saskatchewan
104 Clinic Place
Saskatoon, Saskatchewan
S7N 2Z4

ABSTRACT

People with end stage renal disease (ESRD) face important health-related decisions concerning end-of-life care and the use of life-support technologies. They already require technology to sustain life, relying on dialysis to provide kidney function. People with ESRD have a high risk of cardiac arrest because dialysis worsens cardiac disease. In the case of cardiac arrest, the healthcare team may decide to offer cardiopulmonary resuscitation (CPR) to try to restore function and prolong life. While people often want to be involved in making decisions about their health, there are many challenges. People with advanced illness may have limited or wavering ability to participate fully in decision-making conversations – or lack decisional capacity for making decisions. Additionally, they may have a limited understanding of CPR and tend to receive inconsistent information on the process and outcome of CPR. CPR is less effective in older adults with advanced disease of any kind, resulting in difficult discussions between patients, their families, and healthcare professionals. Unfortunately, these discussions are often avoided. Shared decision-making approaches target overcoming these challenges. The objectives of this research are: 1) to analyze the concept of decisional capacity as it relates to medical decision-making and, 2) to design, test, and analyze a novel CPR video decision aid (VDA) with nephrology patients and their families in a clinical setting. The Interprofessional Shared Decision-making Model was used as a framework to guide the research. Results of from the study indicate that CPR-VDA was feasible and acceptable to patients with ESRD, their families, and the healthcare team in the nephrology setting, even when patients' illness and treatment caused difficulty attending to all aspects of the decision-making process all of the time. The CPR-VDA improved patient and family knowledge about CPR, clarified values around the decision, improved the patients' ability to make a decision about CPR confidently, and reduced decisional conflict (uncertainty) amongst patients, families, and physicians despite any limitations to patient decisional capacity. All patients in the study were able to participate in conversations and decision-making about CPR with the assistance of the CPR-VDA and decision coaching from an advanced practice nurse.

ACKNOWLEDGEMENTS

Thank you everyone! Honestly, if there is one thing I learned during this journey through a thesis project, it takes many people to support the work of a graduate student.

I would like to thank my tireless supervisors, Jennifer Kryworuchko and Wanda Martin. Jen, you inspire me always with your inquisitive brain and kind heart and you terrify me with your boundless energy! Wanda, thank you for taking me under your wing for the last half of my graduate program; your guidance and gentle nudges kept me moving forward.

I would also like to extend gratitude to the students and faculty at the University of Saskatchewan, especially committee members Carol Bullin and Mary Ellen Andrews, and Linda Ferguson for the supportive environment they created for me within the College of Nursing

My family made many sacrifices so that I could study, research and write. I missed many sporting events and school activities but my husband and children cheerfully continued along. Thank you to the grandma's and grandpa who looked after the grandbabies and spoiled them with your attention!

Finally, I could not have completed this research project without the support of the Saskatoon Health Region and especially the patients, families and staff in the Renal Health Unit – this is for them, and hopefully I stayed true to the stories they shared and learned from their experiences.

DEDICATION

My loves:

Peter

Alora

Quintin

Juliette

Table of Contents

TABLES

ACRONYMS

CPR	Cardiopulmonary resuscitation
CPR-VDA	Cardiopulmonary resuscitation video decision aid
ESRD	End stage renal disease
IP-SDM	Interprofessional shared decision-making model
VDA	Video decision aid

Chapter 1 Introduction

The purpose of the thesis project was to use a shared decision-making approach evaluating a novel cardiopulmonary resuscitation (CPR) video decision aid (VDA) with patients with advanced illness and their families making decisions about whether or not they wanted cardiopulmonary resuscitation as part of their care plan. This study is about the impact of using the CPR-VDA with patients diagnosed with end stage renal disease (ESRD) who have already made a similar complex decision, to receive hemodialysis. The study aim was to ensure that doctors and nurses provided CPR only when wanted by patients with ESRD, and to improve their knowledge and involvement in decisions about their care. This work includes an exploration of the concept of decisional capacity, an important aspect to decision-making with seriously ill older adults. The project was part of a larger research program aimed at improving the quality of communication during decision-making processes involving patients with advanced illness, their families, and the healthcare team.

1.1 Problem Statement

Patients with ESRD face important health related decisions, including palliative end-of-life care, and if they want life-support technologies in their care (Murray, Bissonnette, Kryworuchko, Gifford, & Calverley, 2013). ESRD is the final stage of kidney disease where kidneys are working at less than 15% of their normal capacity, therefore requiring dialysis or kidney transplantation to sustain life (The Canadian Kidney Foundation, 2015). Patients with ESRD have a higher incidence of cardiac arrest because dialysis treatment exacerbates cardiac disease, thus healthcare providers may offer CPR to try to restore cardiac and respiratory function to prolong life (Herzog, 2003). Unfortunately, CPR does not work well for patients with poor prognosis resulting from advanced medical illness (Davison, 2009; Lafrance, Nolin, Sencal, & Leblanc, 2006). Communication about CPR treatment is lacking in healthcare settings (Heyland et al., 2006; Mirza, Kad, & Ellison, 2005).

Informed discussions are essential to good decision-making and many people prefer to be involved in some kind of shared decision-making about CPR (Frank et al., 2003). However, during CPR discussions, physicians tend not to explore long term outcomes related to CPR in relation to patients' health status, there is large variability in approaches to the conversations, and

no consistency in information content or order presented (Frank et al., 2003; Mallery, Hubbard, Moorhouse, Koller, & Eeles, 2011). This leaves patients and families with poor understanding of the resuscitation process leading to unrealistic expectations of meaningful recovery to baseline health status (Almoosa, Goldenhar, & Panos, 2009; Marco & Larkin, 2008). A shared decision-making approach with a decision aid tailored to CPR was proposed in order to help the patient and family talk to their healthcare team and to facilitate patient-centered care.

This study is an examination of the process of making a CPR decision with patients and their families in the nephrology setting using the Interprofessional Shared Decision-Making Model as the framework, the CPR-VDA intervention, and before and after survey methods. The following thesis contains details of the project and suggests ways to improve communication around important health care decisions. Chapter 1 contains the supporting background information about decision-making, CPR, barriers to CPR communication, and the development of the CPR-VDA. The chapter also contains a review the Interprofessional Shared Decision-making Model (IP-SDM) that guided this research and an outline of the research studies undertaken during the project, as well as contributions of co-authors.

1.2 Background

1.2.1 Decision-making for Patients with End Stage Renal Disease

The care of older patients involves the increasing use of medical technologies towards the end-of-life, particularly for patients with advanced medical illness, multiple comorbidities or life limiting medical conditions such as ESRD (Heyland et al., 2013). As well, there has been a gradual but definite shift in health care decision-making from a paternalistic medical model towards shared decision-making with patient and family and their healthcare team (Mitchell et al., 2012). As patients and family members increasingly are required to make complex decisions, they are challenged by a lack of medical knowledge, low health literacy, uncertainty about their prognosis, and limited capacity to make decisions. Researchers have argued that the health care system has not responded with sufficient education, engagement, and support in the decision-making process (Jones, Podolsky, & Greene, 2012). Indeed, for medical, social, cultural, and legal reasons, many physicians are reluctant to engage patients nearing end-of-life in advance care planning meaningfully (Jones et al., 2012). What has followed is an increase in technological aggressiveness of care at the end-of-life.

Patients maintain they would prefer less aggressive care if death were likely to occur in the short term (Heyland et al., 2006). Studies have reported that nephrology patients with ESRD felt they are not always part of discussions around prognosis, treatment goals, and end-of-life care (Tong et al., 2014). There is also an increasing awareness that resources and spending at end-of-life is not correlated with quality of life or quality of care well (Wennberg, Fisher, Goodman, & Skinner, 2008). With the shift in age demographic, more than ever, Canadians, older patients, and health care professionals are focused on more meaningful advance care planning and a shared informed decision-making process about the use of technology at the end-of-life.

1.2.2 Cardiopulmonary Resuscitation

CPR is an emergency technique that helps partially restore blood flow and oxygenation to the body when the heart stops. In the early 1960s, CPR was performed on unstable postoperative patients with issues that were temporary and reversible (e.g., overdose of anesthesia or blood loss), and early results were very encouraging (Jude, Kouwenhoven, & Knickerbocker, 1961). Optimistically, this procedure was offered to broader populations such as patients in the hospital and people in the community regardless of medical conditions (Wilder, Jude, Kouwenhoven, & McMahon, 1964). By equipping first responders with CPR skills and automated external defibrillators, studies have demonstrated that survival rates from ventricular fibrillation arrests have improved up to 26 – 40 percent (Mosesso, Davis, Auble, Paris, & Yealy, 1998; White, Hankins, & Bugliosi, 1998). From the mid-1970s, physicians have been increasingly aware of the limitations of CPR as a life-restoring procedure for patients with severe and irreversible underlying medical conditions. CPR effectiveness rates would suggest that *not offering CPR* as the default approach might be more appropriate for *certain patient populations* – those with advanced medical illness and a high near-term risk of death, such as patients with ESRD. While the provision of CPR has increased over the last ten years, and the mechanism of CPR delivery is much more effective due to advocacy efforts and education, unfortunately the rate of survival for hospitalized patients has not changed substantially to the same magnitude (Ehlenbach et al., 2009). Much of this is due to the inherent limitations of CPR effectiveness among patients with advanced medical illness at the end-of-life.

1.2.3 Barriers to Effective Communication about CPR

Research has examined patient involvement in decision-making about the use of life sustaining technologies, particularly involvement of patients with advanced medical illness in decisions about CPR. Important barriers to quality discussions about CPR include: 1) patients and families have a limited understanding of CPR; 2) physicians do not routinely discuss CPR and patients do not initiate discussions despite their interest in being involved; 3) when discussions do occur the information provided is inconsistent (Frank et al., 2003; Kryworuchko, Strachan, Nouvet, Downar, & You, 2016). In five Canadian hospitals, researchers found communication leading to a decision on the use of CPR occurred for up to one-third of patients with advanced medical illness and these patients had poor knowledge of this procedure with only 11.3% being able to describe more than two components (Heyland et al., 2006). For patients with advanced illness - particularly for those with multiple co-morbidities including ESRD - outcomes after CPR are quite poor and are very unlikely to improve beyond what they were prior to arrest (Peberdy et al., 2008). Research shows that patients and their family members often have inaccurate knowledge of the effectiveness of CPR (Heyland et al., 2006). A qualitative study of patients and decision-makers following resuscitation discussions revealed that while a number of participants understood CPR as "being revived" they did not understand the implication that successful CPR consequently resulted in being kept alive on a form of life support (Deep, Griffith, & Wilson, 2008). Most members of the public base their understanding of CPR on medical television programs, which often do not portray CPR or the recovery process accurately (Adams & Snedden, 2006).

This communication failure may occur because healthcare professionals are prepared inadequately for end-of-life discussions and lack the confidence to discuss resuscitation status (Sulmasy, Sood, & Ury, 2008). It is most often the healthcare professionals with the least training (i.e., medical students or resident physicians-in-training) who talk to patients about CPR (Kelley, Gold, Roach, & Fins, 2006). Sometimes patients and their family members think discussions about CPR and end-of-life care are not relevant to their situation or are waiting for healthcare professionals to initiate the conversation (Luckett et al., 2014). Taken together, research in this area suggests that improved communication and decision-making is a high priority target for improving end-of-life care and overall patient centered care (Heyland et al., 2010).

Additionally, other factors contribute to a poor understanding of the CPR decision. One factor may be inadequate health literacy. Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions (Institute of Medicine, 2004). Health literacy is a stronger predictor of health status than age, income, education level, or employment status (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs AMA, 1999). Additionally, health literacy is related independently to a patient's knowledge about their disease and mortality (Baker, Wolf, Feinglass, & Thompson, 2008). Volandes, Paasche-Orlow, et al. (2009) found patients with advanced dementia who viewed a video about interventions to sustain life had improved health literacy regarding decision-making. In particular, older people who viewed a video decision aid (VDA) were more likely to prefer comfort care instead of CPR and life prolonging care, and had more stable preferences over time compared with those who solely listen to a verbal description (Volandes, Paasche-Orlow, et al., 2009). Patients and their substitute decision makers were also more likely to agree about the patient's preferences for CPR and life prolonging technology after viewing a VDA than when solely listening to a verbal description (Volandes, Mitchell, Gillick, Chang, & Paasche-Orlow, 2009). However, VDAs have not been trialed in the process of care. For example, there have been no CPR decision trials with a personal values clarification exercise or worksheet to review in subsequent formal conversations with a healthcare professional. Neither has there been CPR decision research done with patients diagnosed with ESRD who need ongoing advance care-planning discussions revisited periodically as they rely on life-supportive therapy for a life limiting disease. This research builds on preliminary observations but adds to the body of knowledge by exploring their utility with patients and healthcare professionals in the ongoing process of making a decision about CPR.

Early results of a CPR-VDA development study in Saskatoon, Vancouver, and Toronto indicated that acutely ill patients admitted on medical units do not connect the relevance of CPR decisions to their current situation (Kryworuchko, Gallagher, Fowler, Kapell-Brown, & Krawczyk, 2015). However, this may or may not be the case with ESRD patients. It has been well documented in literature that chronic kidney disease and ESRD are major cardiovascular risk factors with cardiac mortality being the leading cause of death in patients with ESRD (Alfonzo, Simpson, Deighan, Campbell, & Fox, 2007; Lafrance et al., 2006). Cardiac arrest is also a known complication of regular, delayed, and terminated dialysis treatments (Alfonzo et

al., 2007). Therefore, it may be reasonable to assume that these patients would recognize the relevance of CPR to their care, and be willing to be involved in decision-making about this treatment.

Decisional capacity generally refers to a patient's ability to participate in decision-making process. Decisional capacity may not be consistent over time; patients with advanced illness experienced fluctuating levels of ability to attend to details of the CPR decision-making process in a meaningful way during the earlier study (Kryworuchko, Gallagher, Fowler, Kapell-Brown, & Krawczyk, 2015). In this study, the fluctuating capacity was managed by stopping the interview and reassessing whether patients recovered decisional capacity after a rest period or on the next day. Because patients and families were interviewed together, at times this fluctuating capacity resulted in increased family engagement in decision-making in place of the patient. Understanding decisional capacity further (Chapter 2: Concept Analysis) is important in the observations of environmental factors that could affect decisional capacity during the subsequent study with ESRD patients and their families (integrated in methods for Chapter 3). This research is timely considering the growing interest in the concept of decisional capacity as it relates to end-of-life care, treatment options such as CPR, withdrawal of care, and medical aid in dying.

1.2.4 Patient Decision Aids

Patient decision aids are evidence-based resources that can identify alternative options, their benefits and harms, and further assist patients to communicate their values and preferences to their healthcare provider (Volk, Llewellyn-Thomas, Stacey, & Elwyn, 2013). Decision aids improve knowledge about medical options and their outcomes, increase accurate risk perception, result in a better match between values and choices, and reduce decisional conflict, indecision and regret about the decision (Stacey et al., 2014). To facilitate a shared decision-making approach, a novel video decision aid was developed to prepare patients, families and their healthcare professionals for the conversation about the CPR decision (CPR-VDA). The narrator's script for the CPR-VDA (Appendix A) was adapted from an earlier paper-based decision aid on the CPR decision (Frank, Pichora, Suurdt, & Heyland, 2010). The paper-based decision aid was developed considering a systematic literature review (Frank et al., 2003) and expert review during focus groups with physicians, nurses, a clinical ethicist, and members of the CARENET research network. The earlier paper-based decision aid was trialed with 25 patients

with advanced illness and 11 of their family members while in hospital and was found to be feasible, acceptable, and helpful to consider information and personal values for decision-making (Frank et al., 2010). It was piloted to get a sense of the acceptability and usefulness for decision-making during three adult focus groups living in the community in Vancouver (n=14) and Kingston (n=30) and with a wider group of CARENET researchers (n=22). Changes were made to the CPR-VDA based on feedback from these groups: clarification of the presentation of data, simplified the language, made explicit the alternative to CPR, compared outcomes of CPR to those without CPR, and further developed the section on patient values. The CPR-VDA is available at http://vimeo.com/48147363. Growing evidence supports the use of patient decision aids in clinical practice (Stacey et al., 2014; Volk et al., 2013).

1.2.5 Nurses' Role in Decision Coaching

The nurses' role in decision coaching is clearly laid out in the Ottawa Decision Support Tutorial (www.decisionaid.ohri.ca/ODST/), an online tutorial provided free of charge by the Ottawa Hospital Research Institute. When patients and families are using patient decision aids for complex health decisions, the nurse can support many aspects of the decision process. Indeed, it would be considered inappropriate to abandon patients and families to such complex decisions, as the one about CPR, without support. As expert communicators, nurses can provide empathetic listening and form therapeutic relationships to support decision-making. For example, the study nurse in Chapter 3 acts as a decision coach and has an explicit and formal role on the interprofessional team regarding decision-making. Nurses can enhance understanding of complex health information, clarify decisions and alternatives, help families communicate values and preferences, and advocate for their preferred role in decision-making. Nurses have a clear ethical and professional obligation to support healthcare decision-making (Canadian Nurses Association, 2008).

1.3 Guiding Conceptual Model

The Interprofessional Shared Decision-making Model (IP-SDM) was used as the framework from which to view the complex communication patterns between healthcare professionals, patients and families during a decision-making process in a nephrology setting (see Appendix A) (Légare et al., 2011). This is a model that changed the communication focus from a traditional physician-patient dyad to include the patient, family, and healthcare team

members (nurse, nephrologist, resident) (Légare et al., 2011). The model highlights the themes of patient and family centered care and patient decision support. These are key concepts in the current healthcare system (Government of Saskatchewan, n.d.) and therefore are relevant to Canadian healthcare. Features of the model include the following five components: (1) placing patient at the center; (2) patient support from more than one interprofessional healthcare provider as well as family or significant others who are important to the patient; (3) information exchange of relevant evidence-based information, options, risks and benefits of the healthcare situation in relation to patient values and preferences; (4) actual choice voluntarily agreed upon by all; and (5) choice implemented. The process may happen all at once or be staggered in many steps as deliberation occurs (Légare et al., 2011).

The IP-SDM has been validated by stakeholders in primary and acute care and is being used in research projects for clinical practice to support decision-making at multiple levels. Since multiple healthcare professionals work with ESRD patients and their families, a team-based approach to supporting shared decision-making was preferred by the clinical team that we worked with for the research.

Decisional capacity is an assumption of the model but there is no formal criterion outlined about its' measure. Use of decision aids, evidence based tools tailored to deliver disease specific information, options and alternatives, along with prospective benefits and harms, can help prepare patients and their families for the decision-making process (Elwyn et al., 2006; A. M. O'Connor, Graham, & Visser, 2005). As well, the use of decision coaching by a healthcare team member can provide nondirective guidance to assess decisional needs and tailor support to meet those identified needs.

The power of the IP-SDM, as it relates to decisional capacity, resides with the family/surrogate/significant other involved who can have a pivotal role in identifying capacity issues, and including the patient's values, preferences and preferred choice even when the patient's capacity is diminished to some degree. The model also accommodates the wavering capacity of the patient with the relational propositions allowing for movement back and forth between steps with multiple points of assessment and discussion with the key stakeholders. While the IP-SDM does not identify which professionals are responsible for specific roles, the decision coach role is consistent with the role of nursing. Nurses in the decision coach role have clinical context, are continually assessing patient and family needs, provide education, create

space to discuss and clarify patient values, and identify supports and barriers while advocating for inclusion of the patient in their own care decisions (Canadian Nurses Association, 2008; Stacey et al., 2013; Stacey et al., 2012).

1.4 Methodological Approach

This study includes a concept analysis of decisional capacity, using a hybrid model by Schwartz-Barcott and Kim (2000) to define decisional capacity as it applies to nursing and allied healthcare professionals. The hybrid model combines clinician perspectives with field experience and theoretical analysis to provide a deep understanding of the phenomena of interest, and is explained in detail in Chapter 2. The concept analysis was followed by a prospective quasi-experimental intervention study of the CPR-VDA with ESRD patients, families, and physicians (Chapter 3). Chapter 3 details the data collection and analysis. The study outcomes included pre/posttest measures of knowledge and confidence in decision-making, and posttest only measure of uncertainty about the decision (decisional conflict).

1.5 Summary

The purpose of the thesis project was to test and analyze a novel cardio-pulmonary resuscitation video decision aid (CPR-VDA) with nephrology patients and their families in a clinical setting. The ultimate goal of this research is to enhance communication around the decision to have or not have CPR. This project evaluated feasibility of the evaluation process and acceptability of the CPR-VDA for ESRD patients and their families, gathering important information on decisional capacity, the decision aid's impact on knowledge, values, decisional self-efficacy, uncertainty and quality of communication.

The first chapter outlined the problem statement and background issues from a clinical perspective and gave an overview of the guiding theoretical model used for the research. The second chapter provides a concept analysis of decisional capacity, which is a clinical issue identified while planning for the project and further describes the link to the theoretical model. Chapter 3 describes the results of the study and Chapter 4 integrates the results with current advanced nursing knowledge. Contributions of the authors to this manuscript based thesis are listed in Table 1, including contributions of the student researcher (Cherie Kapell-Brown: CKB), as well as thesis supervisors (Jennifer Kryworuchko: JK and Wanda Martin: WM) and faculty member (Linda Ferguson: LF)

Table 1 Contribution of Collaborators

Element	Chapters 1,4	Chapter 2 Manuscript #1 Decisional Capacity: A Concept Analysis	Chapter 3 Manuscript #2 Evaluation Of The CPR With ESRD Patients
Conceptualize & design	CKB, JK	CKB	JK, CKB
Collect data	CKB	CKB	CKB
Analyze & interpret data	CKB, JK, WM	CKB	CKB, JK, WM
Draft manuscript	CKB	CKB	CKB
Revise manuscript for important intellectual content	CKB	CKB, JK, WM, LF	CKB, JK, WM
Approve final version prior to publication	CKB, JK, WM	CKB, JK, WM, LF	CKB, JK, WM
Responsible for overall content	CKB	CKB	CKB

1.5 References

Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs AMA. (1999). Health literacy: report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. *JAMA: Journal of the American Medical Association, 281*(6), 552.

Adams, D. H., & Snedden, D. P. (2006). How misconceptions among elderly patients regarding survival outcomes of inpatient cardiopulmonary resuscitation affect do-not-resuscitate orders. *The Journal of the American Osteopathic Association, 106*(7), 402.

Alfonzo, A. V. M., Simpson, K., Deighan, C., Campbell, S., & Fox, J. (2007). Modifications to advanced life support in renal failure. *Resuscitation, 73*(1), 12-28. doi:10.1016/j.resuscitation.2006.07.019

Almoosa, K. F., Goldenhar, L. M., & Panos, R. J. (2009). Characteristics of discussions on cardiopulmonary resuscitation between physicians and surrogates of critically ill patients. *Journal of Critical Care, 24*(2), 280-287. doi:10.1016/j.jcrc.2009.03.002

Baker, D., Wolf, M., Feinglass, J., & Thompson, J. (2008). Health Literacy, Cognitive Abilities, and Mortality Among Elderly Persons. *Journal of General Internal Medicine, 23*(6), 723-726. doi:10.1007/s11606-008-0566-4

Canadian Nurses Association. (2008). *Code of Ethics for Registered Nurses*. Author: Ottawa, ON.

Davison, S. N. (2009). Advance care planning in patients with end-stage renal disease. *Progress in Palliative Care, 17*(4), 170-178.

Deep, K. S., Griffith, C. H., & Wilson, J. F. (2008). Discussing preferences for cardiopulmonary resuscitation: What do resident physicians and their hospitalized patients think was decided? *Patient Education and Counseling, 72*(1), 20-25. doi:10.1016/j.pec.2008.01.017

Ehlenbach, W. J., Barnato, A. E., Curtis, J. R., Kreuter, W., Koepsell, T. D., Deyo, R. A., & Stapleton, R. D. (2009). Epidemiologic study of in- hospital cardiopulmonary resuscitation in the elderly.(Report)(Statistical data). *The New England Journal of Medicine, 361*(1), 22.

Elwyn, G., O'Connor, A., Stacey, D., Volk, R., Edwards, A., Coulter, A. (2006). Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ.333(7565):417*.

Frank, C., Heyland, D. K., Chen, B., Farquhar, D., Myers, K., & Iwaasa, K. (2003). Determining resuscitation preferences of elderly inpatients: a review of the literature. *CMAJ : Canadian Medical Association Journal, 169*(8), 795.

Frank, C., Pichora, D., Suurdt, J., & Heyland, D. (2010). Development and use of a decision aid for communication with hospitalized patients about cardiopulmonary resuscitation preference. *Patient Education and Counseling, 79*(1), 130-133. doi:10.1016/j.pec.2009.08.002

Government of Saskatchewan. (n.d.). Patient- and Family-Centred Care. Retrieved from https://www.saskatchewan.ca/government/health-care-administration-and-provider-resources/saskatchewan-health-initiatives/patient-and-family-centred-care

Herzog, C. A. (2003). Cardiac arrest in dialysis patients: approaches to alter an abysmal outcome. *Kidney International, Supplement*(84), S197-S200.

Heyland, D. K., Barwich, D., Pichora, D., Dodek, P., Lamontagne, F., John, J. Y., . . . Simon, J. (2013). Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Internal Medicine, 173*(9), 778-787.

Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Skrobik, Y., . . . Cohen, S. R. (2010). Defining priorities for improving end-of- life care in Canada. *CMAJ : Canadian Medical Association Journal, 182*(16), E747. doi:10.1503/cmaj.100131

Heyland, D. K., Frank, C., Groll, D., Pichora, D., Dodek, P., Rocker, G., & Gafni, A. (2006). Understanding cardiopulmonary resuscitation decision making: perspectives of seriously ill hospitalized patients and family members. *Chest, 130*(2), 419.

Institute of Medicine. (2004). *Health literacy : a prescription to end confusion*. Washington, D.C.: National Academies Press.

Jones, D. S., Podolsky, S. H., & Greene, J. A. (2012). The burden of disease and the changing task of medicine. *The New England Journal of Medicine, 366*(25), 2333. doi:10.1056/NEJMp1113569

Jude, J. R., Kouwenhoven, W. B., & Knickerbocker, G. G. (1961). Cardiac arrest. Report of application of external cardiac massage on 118 patients. *JAMA: Journal of the American Medical Association, 178*, 1063.

Kelley, A. S., Gold, H. T., Roach, K. W., & Fins, J. J. (2006). Differential Medical and Surgical House Staff Involvement in End-of- Life Decisions: A Retrospective Chart Review.

Journal of Pain and Symptom Management, 32(2), 110-117. doi:10.1016/j.jpainsymman.2006.02.009

Kryworuchko, J., Fowler, R., Kapell-Brown, C., Krawzyk, M., Gallagher, R. (2015). Evaluation of a Cardiopulmonary Resuscitation Decision Aid to Promote Shared Decision Making (Poster, Abstract). *International Shared Decision Making Conference*, Sydney, Australia.

Kryworuchko, J., Strachan, P.H., Nouvet, E., Downar, J., You, J. (2016). Factors influencing communication and decisionmaking about life-sustaining technology during serious illness: a qualitative study. *BMJ Open* 6:e010451. doi:10.1136/bmjopen-2015-010451

Lafrance, J.-P., Nolin, L., Sencal, L., & Leblanc, M. (2006). Predictors and outcome of cardiopulmonary resuscitation (CPR) calls in a large haemodialysis unit over a seven-year period. *Nephrology Dialysis Transplantation, 21*(4), 1006-1012. doi:10.1093/ndt/gfk007

Légare, F., Stacey, D., Pouliot, S., Gauvin, F.-P., Desroches, S., Kryworuchko, J., . . . Graham, I. D. (2011). Interprofessionalism and shared decision- making in primary care: a stepwise approach towards a new model. *Journal of Interprofessional Care, 25*(1), 18-25. doi:10.3109/13561820.2010.490502

Luckett, T., Sellars, M., Tieman, J., Pollock, C. A., Silvester, W., Butow, P. N., . . . Clayton, J. M. (2014). Advance Care Planning for Adults With CKD: A Systematic Integrative Review. *American Journal of Kidney Diseases, 63*(5), 761-770. doi:10.1053/j.ajkd.2013.12.007

Mallery, L., Hubbard, R., Moorhouse, P., Koller, K., & Eeles, E. (2011). Specialist Physician Approaches to Discussing Cardiopulmonary Resuscitation for Frail Older Adults: A qualitative study. *Journal of Palliative Care, 27*(1), 12-19.

Marco, C. A., & Larkin, G. L. (2008). Cardiopulmonary resuscitation: Knowledge and opinions among the U.S. general public: State of the science-fiction. *Resuscitation, 79*(3), 490-498. doi:10.1016/j.resuscitation.2008.07.013

Mirza, A., Kad, R., & Ellison, N. M. (2005). Cardiopulmonary resuscitation is not addressed in the admitting medical records for the majority of patients who undergo CPR in the hospital. *The American Journal of Hospice & Palliative Care, 22*(1), 20.

Mitchell, P., Wynia, M., Golden, R., McNellis, B., Okun, S., Webb, C. E., . . . Von Kohorn, I. (2012). Core principles & values of effective team-based health care. *Institute of Medicine*, 32. doi:http://www.iom.edu/tbc

Mosesso, V. N., Davis, E. A., Auble, T. E., Paris, P. M., & Yealy, D. M. (1998). Use of Automated External Defibrillators by Police Officers for Treatment of Out-of-Hospital Cardiac Arrest. *Annals of Emergency Medicine, 32*(2), 200-207. doi:10.1016/S0196-0644(98)70137-4

Murray, M. A., Bissonnette, J., Kryworuchko, J., Gifford, W., & Calverley, S. (2013). Whose Choice Is It? Shared Decision Making in Nephrology Care.(Report). *Seminars in Dialysis, 26*(2), 169.

O'Connor, A. M., Graham, I. D., & Visser, A. (2005). Implementing shared decision making in diverse health care systems: the role of patient decision aids. *Patient Education and Counseling, 57*(3), 247.

Peberdy, M. A., Ornato, J. P., Larkin, G. L., Braithwaite, R. S., Kashner, T. M., Carey, S. M., . . . Praestgaard, A. H. (2008). Survival from in- hospital cardiac arrest during nights and weekends.(Clinical report). *JAMA, The Journal of the American Medical Association, 299*(7), 785.

Stacey, D., Kryworuchko, J., Belkora, J., Davison, B. J., Durand, M.-A., Eden, K. B., . . . Street, R. L. (2013). Coaching and guidance with patient decision aids: A review of theoretical and empirical evidence. *BMC Medical Informatics and Decision Making, 13*(S2), S11. doi:10.1186/1472-6947-13-S2-S11

Stacey, D., Kryworuchko, J., Bennett, C., Murray, M. A., Mullan, S., & Légare, F. (2012). Decision coaching to prepare patients for making health decisions: a systematic review of decision coaching in trials of patient decision aids.(Report). *Medical Decision Making, 32*(3), E22-E33.

Stacey, D., Légaré, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., . . . Wu, J. H. C. (2014). Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews, 1*, CD001431. doi:10.1002/14651858.CD001431.pub4

Sulmasy, D. P., Sood, J. R., & Ury, W. A. (2008). Physicians' confidence in discussing do not resuscitate orders with patients and surrogates. *Journal of Medical Ethics, 34*(2), 96.

The Canadian Kidney Foundation. (2015). The Canadian Kidney Foundation Website. Available: http://www.kidney.ca

Tong, A., Cheung, K. L., Nair, S. S., Kurella Tamura, M., Craig, J. C., & Winkelmayer, W. C. (2014). Thematic Synthesis of Qualitative Studies on Patient and Caregiver Perspectives on End-of-Life Care in CKD. *American Journal of Kidney Diseases, 63*(6), 913-927. doi:10.1053/j.ajkd.2013.11.017

Volandes, A. E., Mitchell, S. L., Gillick, M. R., Chang, Y., & Paasche-Orlow, M. K. (2009). Using Video Images to Improve the Accuracy of Surrogate Decision- Making: A Randomized Controlled Trial. *Journal of the American Medical Directors Association, 10*(8), 575-580. doi:10.1016/j.jamda.2009.05.006

Volandes, A. E., Paasche-Orlow, M. K., Barry, M. J., Gillick, M. R., Minaker, K. L., Chang, Y., . . . Mitchell, S. L. (2009). Video decision support tool for advance care planning in dementia: randomised controlled trial. *BMJ, 338*, b2159. doi:10.1136/bmj.b2159

Volk, R. J., Llewellyn-Thomas, H., Stacey, D., & Elwyn, G. (2013). Ten years of the International Patient Decision Aid Standards Collaboration: evolution of the core dimensions for assessing the quality of patient decision aids. *BMC Medical Informatics and Decision Making, 13 Suppl 2*, S1. doi:10.1186/1472-6947-13-S2-S1

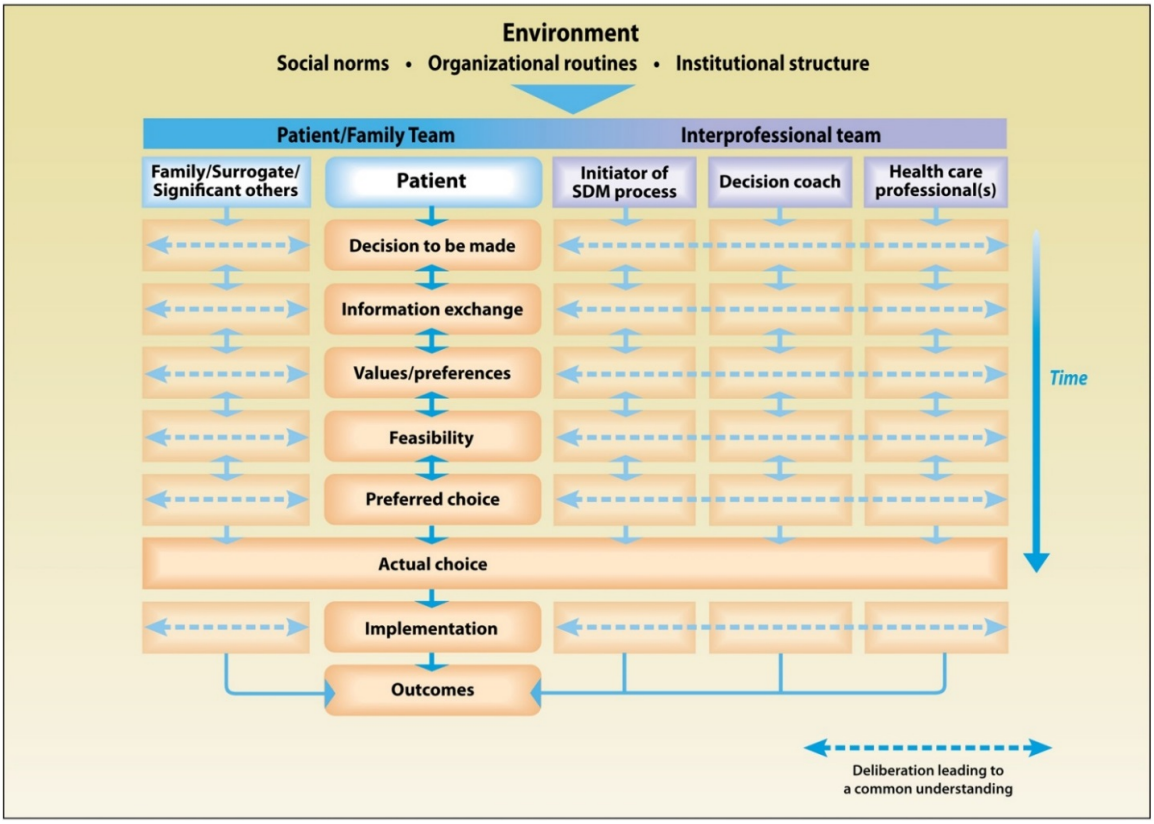
Wennberg, J. E., Fisher, E. S., Goodman, D., & Skinner, J. S. (2008). *Tracking the Care of Patients with Severe Chronic Illness- The Dartmouth Atlas of Health Care.* Dartmouth Centre for Health Policy: Dartmouth NH.

White, R. D., Hankins, D. G., & Bugliosi, T. F. (1998). Seven years' experience with early defibrillation by police and paramedics in an emergency medical services system. *Resuscitation, 39*(3), 145-151. doi:10.1016/S0300-9572(98)00135-X

Wilder, R. J., Jude, J. R., Kouwenhoven, W. B., & McMahon, M. C. (1964). Of 153 attempted--cardiopulmonary resuscitations by trained ambulance personnel--no fatal injuries were produced. *JAMA: Journal of the American Medical Association, 190*, 531.

1.6 Appendix A

Interprofessional Shared Decision-making Model (Légaré F, Stacey D, and IP Team, 2010)



Chapter 2 Manuscript #1 – Decisional Capacity: A Concept Analysis

Current healthcare environments are moving toward providing patient-centered care using interdisciplinary healthcare teams and engaging patients and families in decisions pertaining to their health (Baker, 2014; Dagnone, 2009; Institute of Medicine, 2001; World Health Organization, 2010). The freedom to make decisions is one of the cornerstones of personhood and is rooted in the ethical principle of autonomy (Charland, 2015). When an individual achieves the age of majority there is an expectation that he or she will be able to negotiate the world consciously and make decisions about any number of issues. This requires decisional capacity. What that means, exactly, is not always clear.

A concept analysis aims to provide meaning, definition, and clarity to a concept so that it can be operationalized, used in hypothesis, tested in research, shared in literature, and ultimately improved in clinical practice (McEwen & Wills, 2014). When writers define a concept prior to use, it allows for consistent comprehension by scholars, researchers, practitioners, and readers alike (McEwen & Wills, 2014). The research questions explored in the analysis are: 1) What is the conceptual definition of decisional capacity for adults required to make complex medical decisions? and 2) What is the nature of decisional capacity in health decision-making? In this paper, analysis of the research questions provides a fuller conceptual and operational definition of decisional capacity for nursing practice, followed by a discussion regarding future research ideas.

2.1 Background

A capable adult has the right under Canadian law to make their own health care decisions, which can include consenting to treatment, refusing treatment, and consenting to participate in clinical research (Government of Ontario, 2015). Every Canadian province and most Western Countries have similar laws (Charland, 2015). Although central to legislation and health policy and practice, the concept of capacity itself is ambiguous, with multiple words used to express similar ideas. For example, in the Health Care Consent Act, the terms *capacity* and *capable* are synonymous (Government of Ontario, 2015) however, governments in the United Kingdom and United States of America use the two terms in policy documents with different, but overlapping meanings (Owen et al., 2013). Other synonyms of capacity include *competent*, *qualified* and *wherewithal*. Lack of a clear conceptual definition contributes to difficulties

operationalizing the term in clinical practice, and makes conducting inquiry and research into the phenomena of decisional capacity troublesome; conceptual clarity is necessary to compare findings and inform clinical practice.

Decisional capacity, loosely defined as ability and autonomy in regards to making decisions about one's health, is central to patient-centered care models and shared decision-making approaches (O'Connor, 1995). Having a clearer understanding of the concept *decisional capacity* is vitally important to health professionals (i.e., nurses, clinical ethicists, occupational therapists, physicians) who work with adult patients making complex medical decisions, such as those about requests for use of life-sustaining interventions, accepting invasive interventions, medical assistance in dying, or research involvement (Kolva, Rosenfeld, Brescia, & Comfort, 2014). These health professionals assess patients' capacity to make healthcare decisions in order to determine who requires protection and assistance due to vulnerability, which often arises from illness, poor health, or even health treatments. A study of physicians who regularly assessed *decisional capacity* in their patients reported several problems with these assessments arising from lack of concept clarity and understanding. These included difficulties with consistent assessment across clinicians and availability of a wide variety of cumbersome clinical tools, suggesting further clarification, education, and support is needed in this area (Ganzini, Volicer, Nelson, & Derse, 2003; Seyfried, Ryan, & Kim, 2012). In a review of eight studies reporting recognition of incapacity in adult medical patients, physicians failed to recognize incapacity in 42% of patients determined capable by an independent psychiatrist (Sessums, Zembrzuska, & Jackson, 2011).

There is little research to compare physician assessment with that of other providers such as nurses, but it is clear that determining an individual's mental and physical capacity is an essential assessment skill in the nursing scope of practice (Wagner & Hardin-Pierce, 2014). The Canadian Nurses Association (CNA) Code of Ethics (2008) confirms that the registered nurse has the ethical responsibility "to recognize, respect, and promote a person's right to be informed and make decisions" (p. 11). Specifically, the nurse assesses the capabilities (capacity) of the person, involves patient, family and community to help inform decisions, recognizes the patient's or substitute decision maker's right to refuse care and treatment, remains vigilant to expose power differences in health care, and advocates for the autonomy of their patient (Canadian Nurses Association, 2008). Because of their focus on forming therapeutic

relationships with patient and family, their knowledge of baseline status and ongoing holistic assessments, and their ethical obligation to advocate for the patient, nurses are well positioned to assess decisional capacity and assist the interprofessional healthcare team in the determination of capacity (Canadian Nurses Association, 2008; Carroll, 2010).

2.2 Methods

This study is an analysis of the concept of decisional capacity using a hybrid model by Schwartz-Barcott and Kim (2000) to define decisional capacity as it applies to nursing and allied healthcare professionals. The hybrid model combines clinician perspective with field experience and theoretical analysis to provide a deep understanding of the phenomena of interest. There are three phases in the model to work through in order to gain clarification: the theoretical phase, the fieldwork phase, and the final analytic phase. The theoretical phase involves selecting a concept and preforming a literature review that uncovers meaning and measurement. The fieldwork phase is a discussion of the concept considering two complex composite cases highlighting the real life experiences of clinicians. The final analytic phase clarifies the concept by weighing, detailing, and writing about findings.

2.2.1 Theoretical Phase

A scan of the literature was completed searching databases MEDLINE, OVID and CINAHL from 1996 – 2016. In an effort to identify relevant articles, the search was conducted using keywords "decision-making" AND "healthcare" AND "older adults" (8242 results). The initial search was further refined using AND ["mental capacity" OR "competence" OR "autonomy" OR "capacity assessment"] to yield 420 articles, and finally narrowed using AND ["capability" OR "informed consent" OR "decision-making capacity" OR "end-of-life care"] resulting in 13 relevant articles for this analysis.

Of the 13 articles used in this study, six were research articles, four were review articles, two were book chapters, and one was a study protocol to develop a measurement tool. The literature from multiple discipline perspectives were reviewed and categorized as whether they provided meaning or measurement for the concept of decisional capacity. This helped to compare and contrast the current definitions as well as determine how the concept had been measured (McEwen & Wills, 2014).

2.2.2 Fieldwork Phase

The fieldwork phase encompassed integration of the literature search with critical reflection of the nurse's role in establishing decisional capacity using compiled case studies to describe the concept further (McEwen & Wills, 2014). Two compiled case studies that highlighted decisional capacity affecting critically ill patients were developed based on personal clinical experience of the lead author working as a critical care nurse on an interprofessional team of expert nurses, physicians, physical therapists, occupational therapists, respiratory therapists and dieticians. These cases represented typical challenges experienced in a critical care area, however did not represent the team's experience with any individual patient or family. The two hypothetical situations highlight a nurse's role supporting families and typical patients with varying levels of decisional capacity.

Hypothetical Case 1: Wavering decisional capacity. Ms. X was a 45-year-old female patient with complete paralysis. She was admitted to the Intensive Care Unit (ICU) and spent many months recovering. Ms. X was originally brought to the unit with respiratory distress from her progressive paralysis. She developed many complications due to a prolonged hospital admission. During Ms. X's ICU admission, her adult daughter was her substitute decision maker. The daughter wanted decision-making support from other family members, which she received most of the time. At the beginning of the patient's admission, Ms. X was kept heavily sedated due to the stress and trauma of being unable to physically move but, when she was awakened, Ms. X was cognitively functional, though without any ability to communicate. Her sedation was eventually weaned off and anti-anxiety medications were given to control stress. She had a tracheostomy site to ease breathing, was able to slightly nod her head yes and no, and was beginning to mouth words. The environment in ICU was busy with the sounds of the ventilator, intravenous pumps beeping, and frequent assessments by healthcare providers who were attending to her and other patients in the unit. The Glasgow Coma Scale, Richmond Agitation-Sedation Scale, and Confusion Assessment Method for ICU were used to assess level of consciousness and agitation but with varying degrees of usefulness as the tools are based on physical and communication abilities and results did not adequately represent her real capacity to understand and contribute to health decisions. Interdisciplinary rounds with the healthcare team were done outside the patient's room and limited interaction occurred between Ms. X with anyone on the team outside of nursing, respiratory therapy, and physiotherapy. Family was

deferred to (when they were available) for health care decisions and although interventions were briefly explained to the patient, such as trials off the ventilator, medication changes, and upcoming tests, there were limited attempts to engage her in health decision-making, despite her increasing ability to communicate.

Hypothetical Case 2: Diminished decisional capacity to assumption of full decisional capacity. Mr. Y, a 64-year-old male, was admitted to ICU with complications from cancer treatments. He had completed two rounds of chemotherapy treatments when he developed signs of respiratory distress, a decreased level of consciousness and kidney failure. During admission, he was emergently intubated and placed on a ventilator. Before his admission, there were undocumented discussions between the patient and his wife where he indicated he wanted to keep fighting to live and this was translated to the healthcare team to mean he wanted all life-saving and life-sustaining measures. The next two days of his stay included several interventions to save and prolong life such as using intravenous blood pressure medications, aggressive ventilation support, dialysis treatment, medications for pain and sedation, nutritional support, and wound care. All of these interventions involved frequent visits by healthcare providers in a brightly lit, noisy environment. The Glasgow Coma Scale, Richmond Agitation-Sedation Scale, and the Confusion Assessment Method for ICU were used to determine his level of consciousness and agitation. Due to his heavy sedation and illness, he was unable to participate in decision-making and his wife, who was his substitute decision maker, was asked about medical decisions. One week later, Mr. Y was optimized to begin breathing on his own and the breathing tube was removed. Over the course of the day, his respiratory status declined and it became apparent that he might need to be intubated again. He started to become agitated and showed signs of a varying level of consciousness and his answers to questions were limited due to his difficulty breathing. The choice was presented to either have the breathing tube put back in or to not have it and choose less aggressive care, using medications to promote comfort but ultimately succumb to his illness. His wife was not in the room at the time of questioning and he did not want her present. Mr. Y declined having the breathing tube put back in and his answer remained the same the following two times the decision was discussed by Mr. Y, the physician and the nurse. His decisional capacity was deemed intact.

2.2.3 Final Analytical Phase

The final analytic phase consists of weighing and discussing the findings in light of the importance the concept has for nursing and the interdisciplinary healthcare team to provide optimal patient-centered care. A table was used to describe similarities and differences in theoretical and operational definitions of decisional capacities including a comparison of tools. Results are described below, along with the practice implications and future research needs for decisional capacity.

2.3 Results and Analysis

2.3.1 Theoretical phase

Thirteen articles contributed to analysis of the meaning and/or measurement of the concept of decisional capacity.

Conceptual Definitions. The 12 of the 13 literature sources on the meaning of decisional capacity defined the concept from the seminal philosophical work of Beauchamp and Childress (2013) and Buchanan and Brock (1989). Decisional capacity, as it pertains to decision-making in healthcare, is the ability for a patient to make a voluntary informed decision regarding his or her own healthcare situation (Beattie, 2009; Carroll, 2010; Charland, 2015; Taylor et al., 2013). Four conditions must be in place to have decisional capacity to make healthcare decisions: 1) express a choice or respond to a necessary decision, 2) understand and relay information about the decision and options, 3) appreciate the decision has significance, and 4) integrate personal values and preferences (Beattie, 2009; Carroll, 2010; Charland, 2015; Grisso & Appelbaum, 1998; Ho, Pinney, & Bozic, 2015; Kolva et al., 2014; Owen et al., 2013; Sessums et al., 2011; Seyfried et al., 2012; Simpson, 2010; Taylor et al., 2013; Tunzi, 2001) (See Table 1).

The literature review also highlights issues around decisional capacity. Generally, the assessment of capacity is through observation and is somewhat subjective, therefore not completely free of assessor bias (Owen et al., 2013; Simpson, 2010). Physicians reported that they do not readily assess or recognize diminished decisional capacity in their patients (Sessums et al., 2011), assessments are time consuming, and research and training in such assessments is lacking (Ganzini et al., 2003; Seyfried et al., 2012). The assessment for decisional capacity is not a global permanent state but is situational and based on context (Ganzini et al., 2003). In healthcare, a patient is deemed to have decisional capacity until proven otherwise. The clinical

judgment of decisional capacity is not a dichotomous yes or no judgment. Instead, decisional capacity is assessed along a continuum where impairment of decisional capacity may be acute or persistent, global or specific, progressive or fluctuating and care must be taken to optimize a person's ability to be autonomous in decision-making (Beattie, 2009).

It is uncertain, however, how many of the criteria that constitute decisional capacity must be present in order to determine whether a person has capacity. It is unknown whether the presence (or absence) of any one criterion determines capacity (or incapacity). Inherent in a scale score or current dichotomous determinations of capacity is the idea that there is some threshold to be met for determining capacity (i.e., 5/7 criteria must be present). The influence of context is unclear in the literature, although there can be a 'threshold' of capacity based on the situation and the level of risk the decision carries. For instance, a patient with capacity issues may be deemed able to decide to receive personal care but deemed unable to decide whether to have a surgical intervention.

Operational Definitions. The results of this literature review revealed there are few standardized tools for operationalizing (measuring) decisional capacity (Seyfried et al., 2012). A number of tools have been developed and used both clinically and in research to measure decisional capacity with varying degrees of success (Sessums et al., 2011; Simpson, 2010). A psychiatrist's determination of decisional capacity has historically been the gold standard from which other assessment tools are compared (Sessums et al., 2011). However, it is not feasible in a clinical or research setting to always gain the advice of a psychiatry consult, which is why assessment tools have been developed and implemented along with education about how to conduct assessments (Seyfried et al., 2012).

The tools found in this review measure some, but not all, elements of decision capacity (Table 2). Three tools had the ability to measure some aspects of decisional capacity in an office visit and are based on Canadian (and US) laws: the Aid to Capacity Evaluation (ACE), the Hopkins Competency Assessment Test (HCAT) and the Understanding Treatment Disclosure (UTD) evaluation (Sessums et al., 2011). Among these, the validation process for the ACE has been based on the results from larger samples, uses the patient's own medical situation and decision options, is available free online, and comes with an evaluator manual. The HCAT and UTD both use fictional situations and are followed by open and close-ended questions to assess capacity. Another tool, the Mini-Mental State Examination (MMSE), which measures cognitive

ability, was used alongside the ACE, HCAT and UTD tools to aid capacity determination although MMSE correlates with decisional capacity assessments only at extreme scores (Sessums et al., 2011). Cognitive impairment highly correlates with loss of decisional capacity (Owen et al., 2013). Other decisional capacity research focused on the MacArthur Competence Assessment Tool-Treatment (MacCAT-T), which was also designed to measure understanding, appreciation, reasoning, and expressing a choice in a lengthy semi-structured interview format. However, the MacCAT-T does not have a total score or threshold that represents decisional capacity present or absent and is not a free tool (Kolva et al., 2014; Owen et al., 2013; Tunzi, 2001). None of the tools explicitly evaluated whether a person could identify and integrate personal values into decision-making. All of the tools require the patient to be alert and verbal, and there is an expectation that capacity decisions would ultimately be made by the clinical judgment of an expert (Kolva et al., 2014; Owen et al., 2013; Sessums et al., 2011; Tunzi, 2001). Indeed, the majority of practitioners and researchers continued to rely on focused clinical assessment, expert judgment and psychiatric consults to assess decisional capacity alongside or in place of formalized decisional capacity tools (Seyfried et al., 2012).

Table 2 Tools that measure Decisional Capacity

Tool	Identify decision to be made	Understand information	Relay (communicate) information	Appreciate significance /impact of decision (outcomes / possible harms/ benefits)	Identify values / preferences	Express Choice
MacCAT-T	✓	✓	✓	✓	No	✓
ACE	✓	✓	✓	✓	No	No
HCAT	✓	✓	No	No	No	No
UTD	✓	✓	✓	No	No	No
MMSE	No	✓	✓	No	No	No

2.3.2 Fieldwork phase

Two historical case compilations based on the clinical work of experts caring for critically ill adult patients were used here to highlight the concept of decisional capacity. Both cases highlighted the concept of decisional capacity in critically ill adult patients facing life supportive medical decisions. In the author's clinical practice in the Intensive Care Unit, members of the health care team to definitively capture the decisional capacity criteria of understanding, appreciation, reasoning, expressing a choice, and capturing values used no formal measurement tools. In fact, the basis of the team's determination of decisional capacity to make healthcare decisions was on relationships formed with the patients, clinical judgment, nursing assessments, and observations.

In the first case study about Mrs. X and her adult daughter, the nurse could have provided more support. For example, Mrs. X was seriously ill and not always able to make her own decisions. Clinical judgment about Mrs. X's decisional capacity was based on the healthcare team's assessment about her ability to understand and communicate information, as she had limited physical ability due to her tracheostomy. They did not assess other aspects of decisional capacity such as her ability to identify values or process or use other ways to communicate. Her daughter should be included because she was needed to support necessary decisions. The nurse could have a supportive role ensuring the daughter was included in rounds along with the patient, as much as she was able to enhance shared decision-making.

In the second case study about Mr. Y, the patient made the decision himself. He assumed the role of full capacity, not needing the support of his family. He was able to provide direction for his care. However, his lack of inclusion of his family could have resulted in challenging bereavement for his wife. The nurse could have supported his wife to understand his decision-making process and preferences for care.

As illustrated in each of the hypothetical cases, the healthcare professionals would have placed decisional capacity on a continuum rather than a dichotomy. The hypothetical cases illustrated various factors that could affect capacity and cause it to waver moment-to-moment, including personal, environmental, and social factors that include physical status, disease process, medications, sleep patterns, sedation, pain, comfort, anxiety, noise, lighting, visitors, and ability to communicate. The cases served to highlight potential inconsistencies between the ways capacity is defined conceptually in the literature (a dichotomy where a person either has

capacity or not to make a given decision). For example, although patients are deemed to have decisional capacity until proven otherwise, in the case studies it seems like the opposite has occurred. These inconsistencies highlight the relational, contextual way that assessment for decisional capacity might be integrated into practice.

2.3.3 Final Analytic Phase

The current meaning of decisional capacity to make health care decisions is based upon a person being able to express that a choice or a decision is needed, being able to understand and relay information that is presented on the decision and options, appreciate the decision has significance, and rationalize the decision to be consistent with personal values and preferences. Healthcare professionals understand decisional capacity in terms of their relationship with the patient and the contextual factors that might affect capacity along a continuum. This more comprehensive definition has been neither fully realized in the clinical setting as it pertains to the practice of nursing, nor in the literature. We showed that measurement tools measure some but not all of the accepted criteria that make up the definition of capacity in a clinical setting. Furthermore, the literature is not clear about how nurses (or other healthcare professionals) ought to support patients or their families when criteria are not met. It would be helpful to understand how to integrate substitute decision makers when a patient meets some criteria, but not all, and when and how to best support patients in medical decision-making. Nevertheless, the literature seemed unanimous that determining decisional capacity is of high value for the patient and must be promoted and protected by members of the health care team.

The case studies provided clinical evidence that decisional capacity is an integral concept in practice for healthcare providers looking after seriously ill patients. While decisional capacity is currently a static yes/no, all or nothing, assumption, excluding patients who could contribute in some way to their decision-making is problematic to implementing a shared decision-making approach. Some aspects of decisional capacity may be present while others are not. Patients and families regardless of their decisional capacity could be encouraged as much as possible with support to participate using a shared decision making approach. Clinicians need frequent and comprehensive assessments that include each of the elements of decisional capacity to ensure they make a proper clinical judgment about how to best support patient centered decision-making prior to initiating a decision-making process or exchange of information.

Decisions that need to be made in the event of serious or critical illness are complex and have potentially life altering effects, therefore decisions made need to be supported, fully informed, and based on patient values and preferences (Légare et al., 2011). Nursing has a pivotal role in the interprofessional team, however, optimizing this role requires that nursing's engagement in health decision-making be further studied and explored.

The concept analysis has offered a more comprehensive theoretical understanding of decisional capacity as integrated in each step of the shared decision-making process where multiple healthcare professionals may actively facilitate patient and family involvement.

2.4 Future research

Decisional capacity means that an individual must identify that a choice or decision was needed, understand and relay information about the options, appreciate the significance of the decision, and integrate personal values and preferences in their choice. Four aspects of decisional capacity highlighted in the concept analysis were that 1) decisional capacity had many elements that can be supported during decision-making, 2) no measurement tools measured all of the elements of decisional capacity, 3) there was no specific score or threshold identified in the literature that establishes when a person does/does not have capacity, and 4) decisional capacity was potentially affected by contextual factors and therefore may waver or change over time or decision. In order to capture challenges to decisional capacity in the subsequent CPR-VDA trial (next chapter), regular intentional observations of factors that could affect decisional capacity (decisional capacity observation matrix) could be included.

The *decisional capacity* concept analysis also reveals gaps in the literature that might be explored in future research. Although decisional capacity consists of a broader set of elements, it is unknown whether all or only some of these elements needs to be present to ensure high quality decisions. Furthermore, measurement tools could be developed to evaluate decisional capacity and to improve health professional assessments of decisional capacity. There is no exploration of the impact of using different assessment tools on establishing where on the continuum of decisional capacity a patient might find himself or herself, and the potential consequences of using such tools to match decisional needs with targeted support. Further exploration could facilitate a capabilities approach to wavering decisional capacity and reflect a commitment to engage the patient in health care decisions at their level.

2.5 Conclusion

Decisional capacity is a concept integral to nurses as well as other members of the interprofessional healthcare team at both the practice and research level. When working with acutely ill people, nurses must be aware of how a rapidly changing clinical picture might affect the cognitive abilities of patients. Nurses should diligently work towards maximizing patients' ability to participate in the decision-making process to the fullest extent possible. Using a framework such as the Inter-professional Shared Decision-making Model (Légare et al. 2011) may be one way to offer insight into how a nurse might include the patient regardless of their decisional capacity in making informed decisions. This is done by highlighting the unique role of the family / surrogate / significant other in deliberation throughout the decision-making process, using decision coaching to open space for patient and family involvement in meaningful dialogue that also integrates the important role of clinical expertise.

2.6 References

Baker, G. R. (2014). *Evidence Boost: A Review of Research Highlighting how Patient Engagement Contributes to Improved Care*. Available: www.cfhi-fcass.ca/SearchResultsNews/2014/08/14/evidence-boost-a-review-of-research-highlighting-how-patient-engagement-contributes-to-improved-care

Beattie, E. (2009). Research Participation of Individuals with Dementia: Decisional Capacity, Informed Consent, and Considerations for Nurse Investigators. *Research in Gerontological Nursing, 2*(2), 94-102.

Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics* (7th ed.. ed.). New York, New York : Oxford University Press.

Buchanan, A. E., & Brock, D. W. (1989). *Deciding for others : the ethics of surrogate decisionmaking*. New York : Cambridge University Press.

Canadian Nurses Association. (2008). *Code of Ethics for Registered Nurses*. Author: Ottawa, ON.

Carroll, D. W. (2010). Assessment of Capacity for Medical Decision Making. *Journal of Gerontological Nursing, 36*(5), 47-52. doi:10.3928/00989134-20100303-03

Charland, L. C. (2015). Decision-Making Capacity. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy*.

Dagnone, T. (2009). *For patients' Sake: Patient First Review Commissioner's report to the Saskatchewan Minister of Health*. Regina, Saskatchewan : Patient First Review Commission.

Ganzini, L., Volicer, L., Nelson, W., & Derse, A. (2003). Pitfalls in Assessment of Decision-Making Capacity. *Psychosomatics, 44*(3), 237-243. doi:http://dx.doi.org/10.1176/appi.psy.44.3.237

Government of Ontario. (2015). Health Care Consent Act, 1996. Available: www.ontario.ca/laws/statute/96h02

Grisso, T., & Appelbaum, P. S. (1998). *Assessing competence to consent to treatment : a guide for physicians and other health professionals*. New York, NY: Oxford University Press.

Ho, A., Pinney, S. J., & Bozic, K. (2015). Ethical Concerns in Caring for Elderly Patients with Cognitive Limitations: A Capacity- Adjusted Shared Decision- Making Approach: A

Capacity- Adjusted Shared Decision- Making Approach. *Journal of Bone and Joint Surgery, 97*(3), e16(11)-e16(16). doi:10.1016/S0021-9355(15)74555-8

Institute of Medicine. (2001). *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academy Press.

Kolva, E., Rosenfeld, B., Brescia, R., & Comfort, C. (2014). Assessing decision-making capacity at end of life. *General Hospital Psychiatry, 36*(4), 392-397. doi:10.1016/j.genhosppsych.2014.02.013

Légare, F., Stacey, D., Pouliot, S., Gauvin, F.-P., Desroches, S., Kryworuchko, J., . . . Graham, I. D. (2011). Interprofessionalism and shared decision- making in primary care: a stepwise approach towards a new model. *Journal of Interprofessional Care, 25*(1), 18-25. doi:10.3109/13561820.2010.490502

McEwen, M., & Wills, E. M. (2014). *Theoretical basis for nursing* (4th ed.). Philadelphia: PA: Lippincott, Williams & Wilkins.

O'Connor, A. (1995). Validation of a decisional conflict scale. *Medical Decision Making, 15*(1), 25.

Owen, G. S., Szmukler, G., Richardson, G., David, A. S., Raymont, V., Freyenhagen, F., . . . Hotopf, M. (2013). Decision-making capacity for treatment in psychiatric and medical in-patients: cross-sectional, comparative study. *The British Journal of Psychiatry, 203*(6), 461-467. doi:10.1192/bjp.bp.112.123976

Schwartz-Barcott, D., & Kim, H. S. (2000). An expansion and elaboration of the hybrid model of concept development. In B. L. Rodgers & K. A. Knafl (Eds.), *Concept Development in Nursing* (2nd ed., pp. 129-159). Philadelphia: Saunders.

Sessums, L. L., Zembrzuska, H., & Jackson, J. L. (2011). Does this patient have medical decision-making capacity?(Clinical report). *JAMA, 306*(4), 420.

Seyfried, L., Ryan, K. A., & Kim, S. Y. H. (2012). Assessment of Decision-Making Capacity: Views and Experiences of Consultation Psychiatrists. *Psychosomatics*. doi:10.1016/j.psym.2012.08.001

Simpson, C. (2010). Decision-making capacity and informed consent to participate in research by cognitively impaired individuals. *Applied Nursing Research, 23*(4), 221-226. doi:http://dx.doi.org/10.1016/j.apnr.2008.09.002

Taylor, D., Masse, L., Ho, A., Rekart, M. L., Tyndall, M., Henry, B., . . . Buxton, J. (2013). A brief tool to assess capacity to consent for medical care among homeless individuals with problematic substance use: study protocol. *Archives of public health = Archives belges de santé publique, 71*(1), 11. doi:10.1186/0778-7367-71-11

Tunzi, M. (2001). Can the patient decide? Evaluating patient capacity in practice. *American Family Physician, 64*(2), 299.

Wagner, K. D., & Hardin-Pierce, M. G. (2014). *High Acuity Nursing* (6th ed.. ed.). Boston: Pearson Education Inc.

World Health Organization. (2010). Framework for Action on Interprofessional Education & Collaborative Practice.

Chapter 3 Manuscript #2 – Evaluation of the CPR Video Decision Aid with Patients with End Stage Renal Disease

Patients with end stage renal disease (ESRD) face important health related decisions, such as decisions about treatment options, palliative end-of-life care and whether life-support technologies are wanted in their care (Murray, Bissonnette, Kryworuchko, Gifford, & Calverley, 2013). ESRD is the final stage of kidney disease where kidneys are working at less than 15% of their normal capacity, therefore requiring intervention to sustain life (The Canadian Kidney Foundation, 2015). All patients with ESRD have had to make decisions through the course of their chronic illness, for example, about screening and diagnostic tests, vascular access, or dialysis modalities. The use of an additional life supportive technology such as cardiopulmonary resuscitation (CPR), if cardiac or respiratory arrest occurs is another important decision for people with ESRD during their healthcare journey. The aim of this study was to improve the quality of communication during CPR decision-making processes involving patients with ESRD, their families and the healthcare team.

Patients with ESRD have a higher incidence of cardiac arrest because dialysis treatment exacerbates cardiac disease. Healthcare providers may offer CPR to try to restore cardiac and respiratory function and prolong life (Herzog, 2003). Unfortunately, CPR does not work very well for patients with advanced medical illness like ESRD and has poor prognosis (Davison, 2009; Lafrance, Nolin, Sencal, & Leblanc, 2006). Initial survival after cardiac arrest may be better if the cardiac arrest occurs in a hemodialysis unit due to availability of equipment, personnel, and vascular access (Lafrance et al., 2006). However, overall survival after cardiac arrest for older adults with advanced chronic illness such as kidney disease remains poor, with less than 20% of patients who receive CPR surviving to hospital discharge (Ehlenbach et al., 2009; Larkin, Copes, Nathanson, & Kaye, 2010; Sehatzadeh, 2015).

Jones, Podolsky, and Green (2012) argue that the health care system has not responded with sufficient education, engagement, and support in the decision-making process. As patients and family members increasingly are called upon to make complex decisions, they are challenged by a lack of medical knowledge, low health literacy, and uncertainty about their prognosis. Indeed, for medical, social, cultural, and legal reasons, many physicians are reluctant to meaningfully engage patients nearing end-of-life in advance care planning (Jones et al., 2012). What has followed is a potentially unwanted increase in technological care at the end-of-life.

For example, when asked, patients maintain they would prefer less aggressive care if death were likely in the short term (Heyland et al., 2006). ESRD patients and their families feel they are not always part of discussions around prognosis, treatment goals, and end-of-life care (Luckett et al., 2014; Tong et al., 2014). Almost 30% of patients over 75 years of age prefer to stop dialysis because they experience unacceptably poor quality of life and therapy intolerance (Muthalagappan, Johansson, Kong, & Brown, 2013). There is also increasing awareness that resources and spending at end-of-life are not well correlated with quality of life or quality of care (Wennberg, Fisher, Goodman, & Skinner, 2008). Canadians, older patients, and health care professionals increasingly are focused on meaningful advance care planning and promoting a shared, informed decision-making process about the use of technology at the end-of-life.

The CPR video decision aid (VDA) is a novel approach to shared decision-making preparing patients, families, and their healthcare professionals for conversations about the CPR decision. Patient decision aids are resources that can identify evidence-based healthcare options, their benefits and harms, and further assist patients to communicate their values and preferences to their healthcare provider (Volk, Llewellyn-Thomas, Stacey, & Elwyn, 2013). Decision aids improve knowledge about the options and their outcomes, increase accurate risk perception, result in a better match between values and choices, and reduce decisional conflict, indecision, and regret about the decision (Stacey et al., 2017).

This study consisted of field-testing the CPR-VDA in a community context with ESRD patients who have already made a similar complex decision to receive dialysis. The study was part of a larger research program aimed at improving the quality of communication during decision-making processes involving patients with advanced illness, their families, and the healthcare team. The aim of this study was twofold: to improve patient and family member knowledge and involvement in decisions about CPR, and to ensure that CPR was provided only when wanted. The hypothesis was that the CPR-VDA would be acceptable to patients and feasible to use to prepare ESRD patients for shared decision-making about CPR. The video would also improve patient and family knowledge, clarify values, resulting in improve congruence between documented orders and patient choice. The patient and their family member would experience minimal residual uncertainty about the decision thereby improving confidence to make the decision.

3.1 Methods

3.1.1 Design

A prospective quasi-experimental design included pre/posttest measures of knowledge and confidence in decision-making, and posttest only measure of uncertainty about the decision (decisional conflict). Research Ethics Board approval was obtained before commencing the study and all participants provided written informed consent. The local patient and family advisory council and health authority partners also approved the study.

3.1.2 Setting and Participants

Participants were recruited between late summer and mid-winter 2015 in an urban inpatient and outpatient hemodialysis center. At these centers, 260 patients receive hemodialysis 6 days per week. A convenience sample of eight physicians who cared for patients with ESRD receiving dialysis was recruited from the hemodialysis centers. Eligible physicians were staff physicians (nephrologists) or residents on their nephrology rotation. Recruited physicians and members from the renal health care team (social worker, clinical nurse specialist, and unit manager) helped identify eligible patients in the hemodialysis program and/or family members and introduced the study. The research nurse then determined the final eligibility of patients and family members who expressed desire to participate.

Eligible patients were over 55 years of age, had stage 5 renal failure, were dependent on dialysis, and could communicate in English. Patients were invited to identify the adult 'family' member who knew them best, including partners, significant others, and/or close friends. The family member had to be 18 years or older, speak and understand English, have capacity to make healthcare decisions, have accompanied the patient to dialysis at least once, and have provided assistance to the patient without pay. Ideally, we wanted to recruit dyads consisting of a patient and their family member with whom they shared healthcare decisions. However, willing patients who could consent were included even without the participation of a family member. Patients without decisional capacity were invited to assent to participate if their family member was a participant.

3.1.3 Intervention

The CPR-VDA is a seven-minute video designed for participants to independently view on a portable screen. The video presents information about CPR and the alternative option (comfort care) as well as information about the patient experience and important health outcomes. A CPR decision worksheet, which included a values clarification exercise (Appendix A), tailored the generic patient decision aid format to the CPR decision, and was completed with the study nurse. The plain language script for the CPR-VDA (Appendix B) was a significant adaptation from an earlier paper-based CPR information tool (Frank, Pichora, Suurdt, & Heyland, 2010), and was informed by a rapid systematic review process of CPR outcomes data. In collaboration with the research team, a cinematographer produced the final video CPR-VDA that is publicly available at http://vimeo.com/48147363. The study nurse provided non-directive support to help participants complete the questionnaires thus preparing them for the discussion with the physician, consistent with of the role of a decision coach in a shared decision framework (Stacey et al., 2013).

3.1.4 Procedure

The study nurse conducted interviews during a scheduled dialysis treatment. The interview commenced with the patient and/or family member once dialysis was initiated and the patient remained physically stable (Table 3). After obtaining consent, a brief chart review was conducted to check documented CPR orders and pertinent health history. Interviews occurred in a semi private place with patients, family, and staff in close proximity.

The first part of the questionnaires included; demographics with a self-reported frailty index and health literacy test, pre-knowledge test about CPR and pre-intervention self-efficacy questions. Following this series of questions, the patient and/or family member viewed the seven-minute CPR-VDA video on an iPad screen. The interview continued with acceptability questions regarding the CPR-VDA video, post-knowledge test questions about CPR, post-decision self-efficacy questions and series of questions to assess any decision conflict related to the CPR decision. The study nurse asked patients their CPR preference after viewing the CPR-VDA and completing the values clarification worksheet.

3.1.5 Outcomes

Acceptability was assessed using eight validated questions about use, amount of information, the length, the clarity, balance in presentation, willingness to recommend to others and overall suitability for decision-making (Barry, Fowler, Mulley, Henderson, & Wennberg, 1995; Sepucha, Ozanne, Partridge, & Moy, 2009). Knowledge about CPR was tested using nine questions developed by the research team. Self-Efficacy is the participants' self-confidence or belief in their abilities in decision-making, and was measured using the Decision Self-Efficacy Scale (Cranney et al., 2002). The scale gave a total score out of 100, and a higher score indicates higher self-efficacy for decision-making. Used to evaluate a decision aid for women with osteoporosis, the reliability of the scale was 0.92 and it correlated with decisional conflict subscales of feeling informed (r=0.47) and supported (r=0.45) (Cranney et al., 2002). Decision conflict was also assessed, which occurs when a patient is uncertain about what course of action is best for them (O'Connor, 1995). The perception of uncertainty is related to modifiable factors such as feeling uninformed, being unclear about personal values for the options, or feeling unsupported in decision-making (O'Connor, 1995). Decision conflict was measured using the low literacy version of the Decision Conflict Scale for patient/family (O'Connor, 1995) where scores lower than 25/100 were associated with decision implementation and scores over 37.5/100 were associated with delayed decisions. The scale has a reliability of 0.78 and has been used in many studies of patient decision aids (O'Connor, 1995; Stacey et. al., 2017). Decisional conflict was also measured using the SURE test (Légaré et al., 2010) in the values clarification worksheet. The reliability of this scale is 0.65 (Légaré et al., 2010). Measurement of relevancy of the CPR decision for the patient at this stage of their healthcare journey was asked before and after viewing the video. After participant(s) completed the pre and posttest questionnaires, they were then invited to complete the paper based values clarification worksheet.

Once all patient/family questionnaires were completed, the physician caring for the patient discussed CPR with the patient and/or family member to assess whether or not they wanted CPR in the event of a cardiac or respiratory arrest. C.K.B. observed this discussion and completed an Observing Patient Involvement (OPTION) tool that assessed physician and patient involvement in shared decision-making. The OPTION instrument was developed to evaluate shared decision-making communication and the reliability of this scale was 0.66 in a study evaluating physician encounters in primary care settings (Elwyn et al., 2005). Responses on a

five-point scale ranged from 'the behavior is not observed' to 'observed and executed to a high standard'. The total summed score range from zero to 48 with higher scores indicating greater competency in shared decision-making (Elwyn et al., 2005). Physicians completed a final questionnaire to report on the communication with patient/family. During the interview time, the study nurse used an observation matrix and field notes. The matrix captured observations such as time of day, distractions, and local environment, before and after the CPR-VDA intervention. The data collection strategy is summarized in Table 3.

Table 3 Data Collection Strategy

Data source	Time period for data collection	Collection tool
Participating Patient / Family	Pre VDA intervention	PART A: Demographics, Frailty Index, Health Literacy Score Knowledge about CPR Decisional Self-efficacy
	CPR-VDA Intervention	View CPR-VDA (http://vimeo.com/48147363) Observation Matrix (i.e., elements of capacity, fatigue, attention)
	Post VDA intervention	PART B: Acceptability Survey Knowledge about CPR Decisional Conflict Scale Decisional Self-efficacy Scale CPR Worksheet
Study Nurse	Patient / Family / Physician participants discuss CPR decision	OPTION
Participating Physician	Post VDA intervention and discussion	PART A: Demographics (completed once only per physician) PART B: Physician Survey (completed after engaging in each discussion about CPR: Decisional Conflict Scale)
Medical record of participating patient	At enrollment (consent) and one week from date of enrollment	Chart Abstraction Tool (co-morbid illnesses, the presence of 'Goals of Care' orders, 'DNR' orders, 'Resuscitation Care-plan' orders and any order related to CPR)
Study Nurse	Initiated at time of enrollment until end of participation	Field notes

3.1.6 Statistical Analysis

Baseline characteristics and outcomes were reported using proportions for categorical variables, and means and standard deviations (SD) for continuous variables. For each outcome of interest, analysis was conducted at the participant level using descriptive statistics and when appropriate, a paired sample t-test for comparing means (before/after). Data management and statistical analyses were conduct using IBM SPSS Statistics (Version 23).

3.2 Results

3.2.1 Demographics

Of those invited to participate, 8/8 (100%) physicians accepted, 49/53 (92%) patients accepted, and 8/9 (89%) family members accepted (Table 4). Of the five people who declined to participate, four were not interested and one patient was unable to complete the interview due to declining health status. There were seven patient/family member dyads and one family member who participated without the patient. Physicians were mostly experienced clinical nephrology staff and some had either palliative care experience or training about goals of care communication. Fewer than half of patients were female, half were married, and the average age was 67 years. Most patients lived in their own home in an urban setting where they received dialysis. Still, one third of the patients were from a rural area and travelled into the city for treatment. Patients had relatively high health literacy score despite having high school or less education. Over half of patients considered themselves vulnerable to severely frail and most had prior communication about CPR, which varied in formality.

Table 4 Demographics - Patient and Family

Demographic	Patient n=49	Family n=8
Age M (range, SD)	67 (55-91, 9.66)	62 (48-72, 8.19)
Female n (%)	21 (43 %)	5 (63 %)
Marital Status		
Married or living as married	28 (57 %)	8 (100%)
Widowed	10 (21 %)	0
Never married	5 (10 %)	0
Divorced or separated	6 (12 %)	0
Rural	15 (31 %)	5 (63 %)
Urban	34 (69 %)	3 (37 %)

Living Arrangement		
Home	36 (74 %)	8 (100 %)
Retirement residence	8 (16 %)	0
Long-term care or nursing home	4 (8 %)	0
Assisted living	1 (2 %)	0
Highest Education		
Elementary school or less	3 (6 %)	0
Some high school	17 (35 %)	1 (12.5 %)
High school graduate	11 (24 %)	4 (50 %)
Some college/trade school	8 (16 %)	0
College/trade school diploma	2 (4 %)	0
Some university	4 (8 %)	1 (12.5 %)
University graduate	4 (8 %)	1 (12.5 %)
Graduate degree	0	1 (12.5 %)
Health Literacy (out of 8) M (range, SD)	6.61 (0-8, 2.42)	8 (8, 0)
Importance of Religion n (%)		
Extremely important	6 (12 %)	1 (12.5 %)
Very important	16 (33 %)	3 (37.5 %)
Somewhat important	14 (29 %)	3 (37.5 %)
Not very important	8 (16 %)	1 (12.5 %)
Not at all important	4 (8 %)	0
Don't know	1 (2 %)	0
Prior communication about CPR? Yes	30 (61 %)	6 (75 %)
Patient Frailty		
Very fit	0	
Well	3 (6 %)	
Managing well	19 (39 %)	
Vulnerable	18 (36 %)	
Mildly frail	5 (11 %)	
Moderately frail	2 (4 %)	
Severely frail	2 (4 %)	

M=mean; SD=standard deviation

3.2.2 Feasibility and Acceptability

All patient and family member participants viewed the CPR-VDA and completed the values clarification worksheet during the interview time. Each had a follow-up discussion with their physician, although the discussion did not always occur on the same day as the initial interview. After viewing the CPR-VDA and completing the worksheet, participants were clear about the necessary decision, knew the options, could articulate their values, and could discuss these in varying degrees of detail. They were also able to identify their support person(s), decision-making needs and make a plan for next steps. During the video viewing, challenges included poor lighting, disruptive noise, physical discomfort (i.e., vascular access in their arm / needle in arm) positioning for treatment, fatigue, thirst, and confusion over wording. Multiple interruptions in the busy environment affected some people's ability to attend to detail during the interview / intervention process resulting in 6% (3/49) of patients needing to review parts of the video. While working through the values clarification worksheet, participants revealed emotional struggles surrounding their current health state and concerns about the future.

Participants were asked how relevant the decision about CPR was for them before and after the intervention, and while the average rating was that it was relevant to them (2/5), the mean score increased from 2.1 to 2.3 (p=0.01) after the intervention. Ninety-eight percent (56/57) of patient and family member participants rated the CPR-VDA as good to excellent. Seventy-seven percent (44/57) stated it contained the right amount of information, 75% (43/57) thought the information in the video was completely balanced, and 93% (53/57) found the information presented about CPR to be clear. The CPR-VDA was helpful in making decisions about CPR for 89% (51/57) of participants and almost everyone (98%) would recommend the video to other people who are considering CPR (Table 5).

Table 5 Acceptability of CPR-VDA

	Patient n=49		
	Pre	Post	p-value
Relevance of the CPR decision M (range, SD) (Not relevant 0-1-2-3-4 Very relevant)	2.1 (0-4, 1.1)	2.3 (0-4, 1.1)	0.01
Item	Patient n=49 n (%)		Family n=8 n (%)
"How would you rate the CPR video decision aid?"			
Poor	0		0

Fair	1 (2%)	0
Good	19 (38%)	3 (37.5%)
Very good	20 (40.8%)	4 (50%)
Excellent	9 (18.4%)	1 (12.5%)
"How would you rate the amount of information in the video?"		
Much less than I needed	0	0
A little less than I needed	4 (8.2%)	0
About the right amount	37 (75.5%)	7 (87.5%)
A little more than I needed	6 (12.2%)	0
A lot more than I needed	2 (4.1%)	1 (12.5%)
"How balanced was the video's information about CPR?"		
Clearly slanted towards having CPR	4 (8.2%)	0
A little slanted towards having CPR	4 (8.2%)	1 (12.5%)
Completely balanced	38 (77.6%)	5 (62.5%)
A little slanted towards not having CPR	3 (6.1%)	2 (25%)
Clearly slanted towards not having CPR	0	0
"How clear was the information in the video?"		
Everything was clear	29 (59.2%)	7 (87.5%)
Most things were clear	17 (34.7%)	0
Some things were clear	2 (4.1%)	1 (12.5%)
Many things were unclear	1 (2%)	0
"How helpful was the video in helping you make decisions about CPR?"		
Very helpful	28 (57.1%)	4 (50%)
Somewhat helpful	16 (32.7%)	3 (37.5%)
A little helpful	5 (10.2%)	0
Not helpful	0	1 (12.5%)
"Would you recommend this video to other people who are considering CPR?"		
I would definitely recommend it	40 (81.6%)	6 (75%)
I would probably recommend it	8 (16.3%)	2 (25%)
I would probably not recommend it	1 (2%)	0
I would definitely not recommend	0	0

3.2.3 Effectiveness of the Decision Aid

Participant knowledge about CPR increased from a mean score of 4.8/9 (standard deviation [SD]=1.65) before viewing the video to 7.5/9 (SD=1.40) (p=0.000) after viewing the video. Decisional self-efficacy improved slightly from 84% pre intervention (SD 17.04, range

20-100) to 86% after the intervention (SD 14.13, range 39-100) (p=0.005) for patient participants; however, family members' scores remained high in both periods (Table 6). Decisional conflict scores were relatively low overall (scores could range from 0 [no decisional conflict] to 100 [extremely high decisional conflict]); they were higher amongst patients (mean score of 13.57, SD=18.34, range 0-70) but very low amongst family members (mean score of 1.25, SD=3.54, range 0-10). Decisional conflict was also measured for patients using the clinical SURE test on the values clarification worksheet: 14 (28%) patients reported experiencing decisional conflict while 36 (72%) reported no decisional conflict.

Before the intervention, most patients (43/49; 86%) had an order to have CPR in the physician orders and very few (7/49; 14%) had an order not to have CPR. Immediately after viewing the CPR-VDA and completing the values clarification worksheet, fewer 28/49 (57%) chose to have CPR, 13 (27%) chose not to have CPR and 8 (16%) were unsure. Final chart review one week later revealed that fewer patients wanted CPR 36/50 (72%) and more patients 14 (28%) had an order not to have CPR (p=0.007). As is typical in clinical practice, those participants who are unsure will have the default order to have CPR placed in their chart.

After the intervention, a physician discussed the CPR decision with the patient and/or family member with variable quality of patient involvement as assessed using OPTION (M=25.66 SD 7.41, range 9-47, maximum score possible 48). These discussions were held during the patient's dialysis treatment with others (i.e., family, nurse, pharmacist, social work, clinical coordinator, as well as other patients and their families) present in 31/49 (62%) patient conversations. Only the physician and participants were directly involved in the CPR conversation. This is usual practice as the dialysis unit is mostly an open observation unit. In the exit survey, physicians reported the CPR decision as "very relevant" to their patients (M=3.60, SD=0.53, range=2-4), were "very satisfied" with the discussion they had after the intervention (M=3.18, SD=0.79, range=1-4), and reported that the overall discussion was "easy" to have with their patient (M=0.80, SD=0.80, range=0-3) (Table 6).

Table 6 Effectiveness of the Decision Aid

Outcome	Patient n=49			Family n=8		
	Pre	Post	p-value	Pre	Post	p-value
CPR test questions n (%) correct answers						
1. When the heart stops beating, brain death will occur in: *several minutes.*	23 (47%)	40 (81%)		5 (63%)	6(75%)	
2. CPR includes the following treatments: *pressing hard and fast on the breastbone to pump blood through the heart to the body.*	39 (80%)	46 (94%)		7 (88%)	8 (100%)	
3. If CPR is successful and the heart restarts the person: *usually needs a machine to help with breathing, medicines, and fluids while trying to recover in ICU (Intensive Care Unit).*	18 (37%)	39 (80%)		1 (13%)	6 (75%)	
4. The most serious possible harm from the heart stopping and needing to have CPR is: *severe brain damage from lack of oxygen*	32 (65%)	42 (86%)		4 (50%)	8 (100%)	
5. When CPR is effective it will: *restart the heart but have absolutely no effect on other medical conditions.*	25 (51%)	39 (80%)		8 (100%)	8 (100%)	
6. If 100 people have a chronic condition (heart failure, kidney failure, chronic lung disease) and their heart stops, how many will survive CPR and recover well enough to leave the hospital?: *very few people (10 out of 100).*	15 (31%)	43 (88%)		3 (38%)	8 (100%)	
7. If the patient decides NOT to have CPR: *they can receive treatments to relieve suffering AND for other medical conditions if wanted.*	25 (51%)	43 (88%)		6 (75%)	7 (88%)	
8. The healthcare team wants to talk to hospitalized patients about the CPR decision because: *the right decision about CPR depends on what is most important to the individual patient in addition to the patient's medical conditions.*	28 (57%)	43 (88%)		5 (63%)	7 (88%)	
9. Of all the people who survive CPR, how many will have severe brain damage?: *a few survivors.*	30 (61%)	34 (69%)		5 (63%)	7 (88%)	
Knowledge (out of 9) M (range, SD)	4.8 (0-8, 1.65)	7.5 (4-9, 1.40)	0.000	5.6 (4-7, 1.31)	8.1 (6-9, 0.99)	0.000

Decisional Self-Efficacy (0=extremely low; 100=extremely high) M (range, SD)	84 (20-100, 17.04)	86 (39-100, 14.13)	0.005	86 (52-100, 15.98)	92 (77-100, 8.23)	0.203
Certainty						
Decisional conflict scale (0=no conflict; 100=high conflict) M(range, SD)		13.57 (0-70, 18.34)			1.25 (0-10, 3.54)	
SURE n (%)						
4 (no decisional conflict)		36 (72%)				
3		6 (12%)				
2		3 (6%)				
1		3 (6%)				
0 (high decisional conflict)		2 (4%)				
Preference n (%)						
Have CPR		28(57%)				
No CPR		13(27%)				
Unsure		8 (16%)				
Physician Order n (%)						
Have CPR = 1	43(86%)	36(72%)				
No CPR = 2	7 (14%)	14(28%)				
M (range, SD)	1.14(1-2, 0.35)	1.28(1-2, 0.45)	0.007			
Observation of 50 single interactions between each patient/family and physician						
OPTION (score out of 48) M (range, SD)		25.66 (9-47, 7.41)				
Physician Exit Survey						
Relevance of the CPR decision for my patient M (range, SD) (Not relevant 0-1-2-3-4 Very relevant)		3.60 (2-4, 0.53)				
Satisfaction felt with discussion about CPR with patient M (range, SD) (Not at all 0-1-2-3-4 Completely)		3.18 (1-4, 0.79)				
Overall experience with the CPR discussion M (range, SD) (Very easy 0-1-2-3-4 Very Difficult)		0.80 (0-3, 0.80)				

3.3 Discussion

This was the first study to evaluate the use of the CPR-VDA specifically with patients diagnosed with ESRD. Patients with ESRD and their family members valued the CPR-VDA as a tool to help inform and consider decisions about CPR. The initial plan was to recruit patient and

family dyads to participate in the study. However, it was extremely challenging to engage both partners during routine dialysis treatments. Those family members who did participate had special appointments for them to be at a specific treatment. Patients and family members found the CPR-VDA acceptable to use, even when patients' illness and treatment caused difficulty attending to all aspects of the decision-making process all of the time. For the most part, people rated the intervention excellent, contained the right amount of information, balanced, clear, helpful and would recommend it to others.

The CPR-VDA significantly improved knowledge about the CPR decisions. When combined with the values clarification worksheet, the CPR-VDA helped patients consider the options from their own perspective, integrate their own values, highlighted other supports and considerations, supported their confidence in decision-making, and reduced decisional conflict. Our observations are consistent with results of a recent systematic review about the effectiveness of patient decision aids (Stacey et al., 2017). Patient decision aids as a class of intervention are known to improve knowledge about medical options and their outcomes, increase accurate risk perception, result in a better match between values and choices, and reduce decisional conflict, indecision and regret about the decision (Stacey et al., 2017).

Patients were effectively able to utilize the CPR-VDA despite lower formal educational levels. They were continuously able to attend to details in a hectic treatment environment while experiencing considerable health challenges, and varying levels of frailty. Video format patient decision aids may support patients with lower health literacy due to their oral format and flexibility since participants could start, stop, and rewind the video. Furthermore, both an explicit values clarification exercise and a study nurse acting as a decision coach supported participants. These findings support evidence from other studies suggesting video decision aids help patients and families make informed medical treatment decisions (El-Jawahri et al., 2010; Volandes et al., 2012; Volandes et al., 2009).

As decision coach, the study nurse provided important support to patients and families. Patient participants had difficulty navigating questionnaires due to vascular access in their arm, poor lighting, positioning for treatment, and fatigue. Thus the study nurse had a dual role in supporting them to view the video and could not help but to form a therapeutic relationship that included empathetic listening. She was able to focus on subtle changes in patient health status and adjust pacing or timing accordingly, as well as being able to give further clarification when

needed. Activating other members of the healthcare team besides the physician may also be of benefit but was not captured in this efficacy study.

Physicians reinforced the work of the study nurse and the CPR-VDA intervention during their discussion with the patient after the intervention. Thus, the study nurse as decision coach had an explicit and formal role on the interprofessional team regarding decision-making. Optimizing the decision-making environment to increase a patient's ability to meaningfully engage in DM was a clear role for the study nurse providing decision support in this study, and could be taken on by nurses who are part of the clinical team. In this case, the study nurse was an experienced ICU nurse with additional decision coaching training. It is likely that dialysis nurses would need additional preparation or release time to take on the additional role that is fully within their scope of practice. Nurses have a clear ethical and professional obligation to support healthcare decision-making (Canadian Nurses Association, 2008) and their expertise in communications and establishing therapeutic relationships could be utilized to facilitate healthcare decision-making.

3.3.1 Limitations and Future Research

The homogenous sample limits generalization of results to other populations. Recruitment of dyads of patient and family member was challenging because they were busy and not always present at dialysis appointments. Question fatigue was evident among the participants and future studies with this patient population may wish to utilize video or audio recordings to limit fatigue in answering the questions and eliminate the need of the study nurse manually recording answers during the interview. Although there was evidence of above average shared decision-making during the interview and most physicians alluded to the CPR-VDA, the assessment of the patient-physician interview was a very limited measurement as it only considered one interaction between the patient and physician. The conversation was taken out of context of any previous relationship development and / or past conversations about the subject of CPR. Measured over time and across interactions, the overall quality of shared decision-making may have been far greater. The study design would be further strengthened by adding a (randomized) control group to determine the effectiveness of the CPR-VDA intervention. In this study, the CPR-VDA was not compared to usual practice or to a control group and did not randomize the selection of the subjects.

Preparing each member of the healthcare team to support the decision-making process may further support shared decision-making. The lack of team member participation was particularly evident by the lack of support provided to physicians by other healthcare team members in the vicinity of the conversation. Physician members of the healthcare team working at the dialysis center had no instruction or practice using the CPR-VDA and only received a brief overview of the research project from the study nurse. Training in the use of shared decision-making and decision aids could have improved uptake and use of CPR-VDA in the clinical setting. Future interventions and pragmatic effectiveness evaluation could focus on ensuring that healthcare team members are supported to implement the CPR-VDA.

Finally, although this study was formulated around how to best support decision-making about the CPR decision, the decision-making process around life-saving interventions or end-of-life care is not just about arriving at the decision. The decision-making process involves patients and families receiving support for their grief while receiving information about loss, potential loss, or change of health status. The use of the decision aid seemed to open space for other conversations about end-of-life and grieving, which were supported by the study nurse. Anticipatory bereavement was first described by Lindemann (1944) as observations of preparatory grief work done by wives with husbands at war and further conceptualized as a process to prepare terminally ill patients and their families for death thus aiding grieving (Kübler-Ross, 1989). However, most of the research around anticipatory bereavement involves caregivers with very little research focusing on the patients experience with end-of-life decision-making and anticipatory bereavement (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). A future study may be able to reveal connections between the use of patient and family decision support around end-of life care and anticipatory bereavement.

3.4 Conclusion

The CPR-VDA was feasible and acceptable to patients with ESRD, their families and the healthcare team. The CPR-VDA positively affected decision-making: improving patient and family knowledge about CPR, clarity of values, patients' decisional self-efficacy, the congruence between documented physician's orders and patient choice, quality of communication about CPR, while reducing decisional conflict (uncertainty) amongst patients, families, and physicians. The CPR-VDA was useful to patients regardless of their ability to engage in meaningful

conversations with their family and the healthcare team about whether or not to have CPR as part of their care.

Competing Interests

The authors declare there are no competing interests.

Author's Contributions

JK and CKB designed the study, and CKB implemented the study with the guidance and support of JK. CKB met with stakeholders to gain support for the study in each practice setting. CKB recruited, enrolled, and collected data from all participants. CKB inputted and analyzed the data with support from JK and WM. All authors contributed to and accepted the final manuscript.

Acknowledgements and Funding

We would like to thank the patients, family members and healthcare professionals who participated in the study. The research project was supported by The Heart and Stroke Foundation of Canada as part of a larger project, and CKB was supported by an Allied Health Grant from The Kidney Foundation of Canada. Funding agencies had no role in the design, enrollment, data collection, analysis, or writing of manuscript or decision to publish the research. The content is solely the responsibility of the authors.

3.5 References

Barry, M. J., Fowler, F. J., Mulley, A. G., Henderson, J. V., & Wennberg, J. E. (1995). Patient Reactions to a Program Designed to Facilitate Patient Participation in Treatment Decisions for Benign Prostatic Hyperplasia. *Medical Care, 33*(8), 771-782.

Canadian Nurses Association. (2008). *Code of Ethics for Registered Nurses*. Ottawa, ON.

Cranney, A., O'Connor, A. M., Jacobsen, M. J., Tugwell, P., Adachi, J. D., Ooi, D. S., . . . Wells, G. A. (2002). Development and pilot testing of a decision aid for postmenopausal women with osteoporosis. *Patient Education and Counseling, 47*(3), 245-255. doi:10.1016/S0738-3991(01)00218-X

Davison, S. N. (2009). Advance care planning in patients with end-stage renal disease. *Progress in Palliative Care, 17*(4), 170-178.

Ehlenbach, W. J., Barnato, A. E., Curtis, J. R., Kreuter, W., Koepsell, T. D., Deyo, R. A., & Stapleton, R. D. (2009). Epidemiologic study of in- hospital cardiopulmonary resuscitation in the elderly.(Report)(Statistical data). *The New England Journal of Medicine, 361*(1), 22.

El-Jawahri, A., Podgurski, L. M., Eichler, A. F., Plotkin, S. R., Temel, J. S., Mitchell, S. L., . . . Volandes, A. E. (2010). Use of video to facilitate end-of- life discussions with patients with cancer: a randomized controlled trial. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology, 28*(2), 305. doi:10.1200/JCO.2009.24.7502

Elwyn, G., Hutchings, H., Edwards, A., Rapport, F., Wensing, M., Cheung, W.-Y., & Grol, R. (2005). The OPTION scale: measuring the extent that clinicians involve patients in decision- making tasks. *Health Expectations,, 8*(1), 34.

Frank, C., Pichora, D., Suurdt, J., & Heyland, D. (2010). Development and use of a decision aid for communication with hospitalized patients about cardiopulmonary resuscitation preference. *Patient Education and Counseling, 79*(1), 130-133. doi:10.1016/j.pec.2009.08.002

Herzog, C. A. (2003). Cardiac arrest in dialysis patients: approaches to alter an abysmal outcome. *Kidney international. Suppl* (84), S197.

Heyland, D. K., Frank, C., Groll, D., Pichora, D., Dodek, P., Rocker, G., & Gafni, A. (2006). Understanding cardiopulmonary resuscitation decision making: perspectives of seriously ill hospitalized patients and family members. *Chest, 130*(2), 419.

Jones, D. S., Podolsky, S. H., & Greene, J. A. (2012). The burden of disease and the changing task of medicine. *The New England Journal of Medicine, 366*(25), 2333. doi:10.1056/NEJMp1113569

Kübler-Ross, E. (1989). *On death and dying*. London: London : Tavistock/Routledge.

Lafrance, J.-P., Nolin, L., Sencal, L., & Leblanc, M. (2006). Predictors and outcome of cardiopulmonary resuscitation (CPR) calls in a large haemodialysis unit over a seven-year period. *Nephrology Dialysis Transplantation, 21*(4), 1006-1012. doi:10.1093/ndt/gfk007

Larkin, G. L., Copes, W. S., Nathanson, B. H., & Kaye, W. (2010). Pre- resuscitation factors associated with mortality in 49,130 cases of in- hospital cardiac arrest: A report from the National Registry for Cardiopulmonary Resuscitation. *Resuscitation, 81*(3), 302-311. doi:10.1016/j.resuscitation.2009.11.021

Légaré, F., Kearing, S., Clay, K., Gagnon, S., Amours, D., Rousseau, M., & Connor, A. (2010). Are you SURE?: Assessing patient decisional conflict with a 4-item screening test. *Canadian family physician Médecin de famille canadien, 56*(8), e308.

Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry, 101*(9), 141-148.

Luckett, T., Sellars, M., Tieman, J., Pollock, C. A., Silvester, W., Butow, P. N., . . . Clayton, J. M. (2014). Advance Care Planning for Adults With CKD: A Systematic Integrative Review. *American Journal of Kidney Diseases, 63*(5), 761-770. doi:10.1053/j.ajkd.2013.12.007

Murray, M. A., Bissonnette, J., Kryworuchko, J., Gifford, W., & Calverley, S. (2013). Whose Choice Is It? Shared Decision Making in Nephrology Care.(Report). *Seminars in Dialysis, 26*(2), 169.

Muthalagappan, S., Johansson, L., Kong, W. M., & Brown, E. A. (2013). Dialysis or conservative care for frail older patients: ethics of shared decision-making. *Nephrology Dialysis Transplantation, 28*(11), 2717-2722. doi:10.1093/ndt/gft245

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M.-B. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review, 44*, 75-93. doi:10.1016/j.cpr.2016.01.002

O'Connor, A. (1995). Validation of a decisional conflict scale. *Medical Decision Making, 15*(1), 25.

Sehatzadeh, S. a. (2015). *Cardiopulmonary resuscitation in patients with terminal illness: an evidence-based analysis*.

Sepucha, K. R., Ozanne, E. M., Partridge, A. H., & Moy, B. (2009). Is there a role for decision aids in advanced breast cancer?(Report). *Medical Decision Making, 29*(4), 475-482.

Stacey, D., Kryworuchko, J., Belkora, J., Davison, B. J., Durand, M.-A., Eden, K. B., . . . Street, R. L. (2013). Coaching and guidance with patient decision aids: A review of theoretical and empirical evidence. *BMC Medical Informatics and Decision Making, 13*(S2), S11. doi:10.1186/1472-6947-13-S2-S11

Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., . . . Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews, 4*, CD001431. doi:10.1002/14651858.CD001431.pub5

The Canadian Kidney Foundation. (2015). The Canadian Kidney Foundation Website. Available: www.kidney.ca

Tong, A., Cheung, K. L., Nair, S. S., Kurella Tamura, M., Craig, J. C., & Winkelmayer, W. C. (2014). Thematic Synthesis of Qualitative Studies on Patient and Caregiver Perspectives on End-of-Life Care in CKD. *American Journal of Kidney Diseases, 63*(6), 913-927. doi:10.1053/j.ajkd.2013.11.017

Volandes, A. E., Brandeis, G. H., Davis, A. D., Paasche-Orlow, M. K., Gillick, M. R., Chang, Y., . . . Mitchell, S. L. (2012). A randomized controlled trial of a goals-of- care video for elderly patients admitted to skilled nursing facilities. *Journal of Palliative Medicine, 15*(7), 805. doi:10.1089/jpm.2011.0505

Volandes, A. E., Paasche-Orlow, M. K., Barry, M. J., Gillick, M. R., Minaker, K. L., Chang, Y., . . . Mitchell, S. L. (2009). Video decision support tool for advance care planning in dementia: randomised controlled trial. *The BMJ, 338*, b2159. doi:10.1136/bmj.b2159

Volk, R. J., Llewellyn-Thomas, H., Stacey, D., & Elwyn, G. (2013). Ten years of the International Patient Decision Aid Standards Collaboration: evolution of the core dimensions for assessing the quality of patient decision aids. *BMC Medical Informatics and Decision Making, 13*(S2), S1. doi:10.1186/1472-6947-13-S2-S1

Wennberg, J. E., Fisher, E. S., Goodman, D., & Skinner, J. S. (2008). *Tracking the care of patients with severe chronic illness: The Dartmouth Atlas of Health Care.* Dartmouth, New Hampshire: Dartmouth Centre for Health Policy.

3.6 Appendix A: Values Clarification Worksheet

Date: _____ Participant IDs: _____ (patient) _____ (family)

Cardio-Pulmonary Resuscitation (CPR):
A Video Decision Aid for Patients and Their Families

❶ Clarify the decision.

I am being asked to make a decision about whether I want CPR to be a possible option in my (relative's) care.

I will meet with my (relative's) physician in hospital to make this decision soon – today or tomorrow.

❷ Explore your decision.  Knowledge  Values

	FACTS	How much it matters Circle ★s!
Have CPR if my (relative's) heart stops	May live longer	★★★★★
	Survivors are put on life support	★★★★★
	A few survivors will have serious problems with their ability to think after CPR	★★★★★
	Up to 18/100 survive and leave hospital (to home or another setting like a rehab centre)	★★★★★
		★★★★★
Decline CPR – Live as long as you can for as well as you can	CPR doesn't improve illnesses that cause the heart to stop in the first place	★★★★★
	If the heart stops, you become unconscious (unaware of what is happening) and die (natural death)	★★★★★
	Focus on patient dignity & comfort (improve dying process)	★★★★★
	Focus on supporting family	★★★★★
		★★★★★

Certainty

	Patient	Family
Which option do you prefer?	☐Have CPR ☐Decline CPR ☐ Unsure	☐ Have CPR ☐ Decline CPR ☐ Unsure
Are you choosing without pressure?	☐ Yes ☐No	☐ Yes ☐ No

Support

Who else is involved?	Name: _____	Name: _____
Which option do they prefer?	☐ Have CPR ☐ Decline CPR ☐ Unsure	☐ Have CPR ☐ Decline CPR ☐ Unsure

Date: _____ Participant IDs: _____ _____
(patient) (family)

❸ **Identify your (relative's) decision making needs.**

	**Knowledge**	Do you know the benefits and harms of each option?	❑ Yes	❑ No
	**Values**	Are you clear about which benefits and harms matter most?	❑ Yes	❑ No
	**Support**	Do you have enough support and advice from others to make a choice?	❑ Yes	❑ No
	**Certainty**	Do you feel sure about the best choice?	❑ Yes	❑ No

❹ **Plan the next steps based on your needs.**

Decision making needs	Things you would like to try
Knowledge If you feel you do NOT have enough facts	❑ Find out more about the options and the chances of benefits and harms. ❑ List your questions and note where to find the answers (e.g. library, health professionals, counsellors):
Values If you are NOT sure which benefits and harms matter most to you	❑ Review the stars in the balance scale to see what matters most to you. ❑ Find people who know what it's like to experience the benefits and harms. ❑ Talk to others who have made the decision. ❑ Read stories of what mattered most to others. ❑ Discuss with others what matters most to you.
Support If you feel you do NOT have enough support	❑ Discuss your options with a trusted person (e.g. health professional, family, friends). ❑ Find help to support your choice (e.g. funds, transport, child care).
If you feel PRESSURE from others to make a specific choice	❑ Focus on the opinions of others who matter most. ❑ Share your guide with others. ❑ Ask another person involved to complete this guide. Find areas of agreement. When you disagree on facts, agree to get more information. When you disagree on what matters most, respect the person's opinion. Take turns to listen to what the other person says matters most to them. ❑ Find a neutral person to help you and others involved in the decision.
Other factors making the decision DIFFICULT	List anything else you need:

3.7 Appendix B: Video Decision Aid Script

Cardio-Pulmonary Resuscitation (CPR): A Decision Aid for Patients and Their Families
March 27, 2012, 4 minutes

Designed by Jennifer Kryworuchko, Romayne Gallagher, Robert Fowler, and Daren Heyland; building on earlier work by Chris Frank and colleagues (Frank et al., 2010)
Video compilation and editing by Doug Nicolle, Media Services Centre, St Paul's Hospital, Vancouver, BC. Funded in part by Providence Health Care.

There are many decisions you will make when you have chronic illness. If you are sick enough to come to the hospital you may be asked if you would prefer to have cardiopulmonary resuscitation. Cardiopulmonary resuscitation is commonly called CPR. Most people know CPR as the emergency help someone can be given if their heart stops and they collapse on the street. It also is the name given to the treatment that can be given if someone's heart stops while they are in hospital. CPR was first tried on well people who unexpectedly had their heart stop beating. This is now offered to many people in the acute care hospital as well. When the heart stops and doesn't restart again in a couple of minutes, the person dies. In many cases this is a natural and expected event at the end of a serious illness. When patients choose not to have CPR, treatment is still focused on helping you live as well as you can for as long as you can. You will always receive treatment to help you with symptoms such as pain and shortness of breath and care for your needs. Even though your health may be good right now, it is good to talk about whether you prefer CPR to be a possible option in your care. To help you make a decision about whether or not you should receive CPR, we will explain what CPR is, how it is done, what could happen, and whether or not it is effective.

When a person's heart stops beating, that person becomes unconscious within a few seconds because there is not enough blood going to the brain. During this time, the person is not aware of what is happening and does not experience pain. A team of specially trained doctors, nurses, and other professionals provide CPR in the hospital.

CPR can include:

- *Pressing hard and fast on the breastbone to pump blood through the heart to the body*
- *Pushing air into the lungs to get oxygen to the brain*

- *Putting a breathing tube, through the mouth, into the lungs to get air into the lungs more easily*
- *Giving medicines to try and restart the heart*
- *Using electric shock to try and restart the heart*

If the heart is restarted, the person then needs special care and is moved to the Intensive Care Unit. The person will need a machine to help with breathing, medicines, and fluids while trying to recover. This is called being put on life-support. People who survive CPR usually need more medicines and treatments before they may be well enough to leave hospital.

How well CPR works depends on the person's medical condition at the time the heart stops. Studies show that, overall, 18 out of 100 people who undergo CPR in hospital survive and are able to leave the hospital. This means that 82 out of 100 people will die shortly after their cardiac arrest. People who come to hospital with more severe illnesses are less likely to recover after receiving CPR. For example, people with serious chronic diseases like cancers, or heart or kidney disease: only 10 people like this will survive. This means that 90 patients will die. Older people with advanced disease of any kind are more likely to die if their heart stops: only 6 people like this will survive. This means that 94 older patients will die. CPR does not improve the illnesses that caused the heart to stop in the first place. CPR, at best, returns the person to how they were before the heart stopped. Some people do not return to the life they had before this event. Although 13 of the 18 people who survive will return to their home, about 5 of the 18 people who survive are discharged to another setting like a rehabilitation center or nursing home. People who had no thinking problems before the cardiac arrest are usually able to think and communicate well afterwards: 15 of 18 people can think and communicate well but 3 of the 18 survivors will have serious problems with their ability to think.

Some people worry if they say "no CPR", that they will not receive any care at all. This is not true. What you decide about CPR does not change how we care for you. You can still receive treatment to control and improve your illness. This could include antibiotics, intravenous fluids or other medical treatments. You will be offered treatments to help manage symptoms such as pain and shortness of breath and support to meet other needs. We want to help you to live as well as you can for as long as can. Saying "no CPR" means that when the end of your life comes we will still treat you with dignity, and support your family and friends. We will continue to talk

with you regularly about your healthcare. There will be other decisions that need to be discussed as part of your care.

We do not expect you to make difficult medical decisions on your own. Talk with your family, friends, and your health care team about your thoughts, concerns, and wishes. Your family and friends need to understand what is most important to you, in case they have to decide about your health should you become too sick to speak for yourself.

Chapter 4 Integrated Discussion

The research study engaged key community stakeholders to improve the quality of communication during decision-making processes about cardiopulmonary resuscitation (CPR). Our key stakeholders included patients with end stage renal disease (ESRD), their families, and their healthcare providers. The aim was twofold: to improve patient and family member knowledge and involvement in decisions about CPR, and to ensure that CPR was provided only when wanted. Before engaging in the study, the author completed a concept analysis to better understand the operational definition of decisional capacity as it relates to adults required to make complex medical decisions and the nature of the concept in health decision-making (Chapter 2). The main study involved engaging key stakeholders in an efficacy trial of a video decision aid (VDA) aimed at improving the quality of communication during CPR decision-making in a real world setting.

The concept analysis (Chapter 2) resulted in a working definition of decisional capacity for this study. Decisional capacity means that an individual must identify that a choice or decision was needed, understand and relay information about the options, appreciate the significance of the decision, and integrate personal values and preferences in their choice (Beattie, 2009; Carroll, 2010; Charland, 2015; Grisso & Appelbaum, 1998; Ho, Pinney, & Bozic, 2015; Kolva, Rosenfeld, Brescia, & Comfort, 2014; Owen et al., 2013; Sessums, Zembrzuska, & Jackson, 2011; Seyfried, Ryan, & Kim, 2012; Simpson, 2010; Taylor et al., 2013; Tunzi, 2001). Four aspects of decisional capacity highlighted in the concept analysis were 1) decisional capacity had many elements that can be supported during decision-making, 2) no measurement tool measured all of the elements of decisional capacity, 3) no specific score or threshold was identified in the literature that establishes when a person does/does not have capacity, and 4) decisional capacity was potentially affected by contextual factors and therefore may change over time or with respect to particular decisions. While measuring decisional capacity in the subsequent CPR-VDA trial was not possible, regular intentional observations of factors that could affect decisional capacity (decisional capacity observation matrix) were included.

The CPR-VDA study (Chapter 3) was a prospective quasi-experimental design with pre/posttest measures of knowledge and confidence in decision-making, and posttest only measure of uncertainty about the decision (decisional conflict). The initial plan was to recruit patient and family dyads to participate in the study. However, it was extremely challenging to

engage both partners during routine dialysis treatments. For family members who did participate, it was necessary to arrange appointments for them to attend a specific treatment. Due to the repetitive and lengthy nature hemodialysis treatments (usually 3 times per week for 3-4 hours), most family members lived their own lives while the patient was independent/supported by the clinical/research team for CPR decision-making during their treatment appointment. The results of the research study showed that patients with diagnosed ESRD and their family members who viewed the CPR-VDA found it acceptable to use, even when patients' illness and treatment caused difficulty attending to all aspects of the decision-making process all of the time. The CPR-VDA and values clarification worksheet positively affected decision-making: improving patient and family knowledge about CPR, clarity of values, patients' decisional self-efficacy, the congruence between documented physician's orders and patient choice, and quality of communication about CPR, while reducing decisional conflict (uncertainty) amongst patients, families, and physicians. Furthermore, the thesis has aided in understanding more about shared decision-making theory, nurses' roles in interprofessional practice, and health services delivery for patients with ESRD. The integrated discussion provides reflective thoughts on contributions to theory, interprofessional practice, and care delivery, as well as a discussion about implications for research and education (Table 7).

4.1 Integrating Shared Decision-making Theory and Practice

4.1.1 Decision-making process

The IP-SDM was chosen a priori to guide the research. First, the study validated each of the steps in the decision-making process as being relevant for decisions about CPR for ESRD patients, families and physicians. In the first step "identifying the decision to be made", we learned that the intervention was effective to help patients with ESRD understand that the decision was relevant to them (pre-intervention 2.1, post-intervention 2.3, p value 0.01). As well, 92% participation rate for patients and 89% participation rate for families suggested they were willing to consider the CPR decision. Furthermore, physicians in the nephrology setting were willing to engage with their patients to discuss the decision and recognized the importance of improving decision support for their patients; 100% of physicians in the unit participated. During this stage, it might be helpful to integrate an assessment of decisional capacity to ensure that the

right supports are in place for patients to engage in subsequent steps of the decision-making process.

Next, the CPR-VDA was useful to convey accurate information about CPR in an understandable way to patients and their families. All participating patients and families found the decision aid significantly improved knowledge about the CPR decision (patient mean 4.8 pre and 7.5 post, p= 0.000; family mean 5.6 pre and 8.1 post, p=0.000), and 98% of participants rated the CPR-VDA as good to excellent, balanced and clear. Almost all (98%) would recommend the video to others who are considering CPR. When combined with the values clarification worksheet, the CPR-VDA helped patients consider the options from their own perspective, integrate their own values, highlight other supports and considerations, support their confidence in decision-making, and reduce decisional conflict. Physicians personalized the decision about CPR for most patients during the follow-up discussion, for example, explaining how the patient might recover based on their co-morbidities, and the expected quality of life post-resuscitation based on current health status if CPR were to be performed. In this way, patients and families considered the feasibility of having CPR in terms of their own disease process.

The thesis particularly highlights challenges around preferred and actual choice through an extensive discussion of decisional capacity. In particular, decisional capacity seems to rely on a person's ability to engage in each step of the decision-making process: being able to express that a choice or decision is needed, being able to understand and relay information presented on the decision and options, appreciate the decision has significance, and rationalize the decision to be consistent with personal values and preferences. However, if a person can engage in one, but not all, or in most steps of the decision-making process, it is not clear whether they have decisional capacity. There may be value in supporting people to be involved as much as they are capable (a "capabilities approach"), and then using surrogate decision makers to step in where the patient is not able to manage a step in the process independently (Entwistle & Watt, 2013). The case studies showed that decisional capacity is an integral concept in clinical practice for healthcare providers, patients, and families and suggests that healthcare providers need to use frequent assessments to ensure a proper clinical judgment before initiating a decision-making process or exchange of information. The case studies also highlighted that nurses are integral to

the frequent assessments and build relationships with patients and families that aid in creating space for a capabilities approach to decisional capacity.

Then, because the measurement tools do not fully measure all of the criteria that make up decisional capacity in a clinical setting, observations inside the study captured the influences on decisional capacity for patients with ESRD. It was important to be broad in collecting observations of factors that may have affected decisional capacity about the CPR decision. A matrix captured observations such as time of day, distractions, and local environment, before and after the CPR-VDA intervention. From this, it was evident that despite the challenges of poor lighting, disruptive noise, physical discomfort, fatigue, and thirst, most participants could attend to the CPR-VDA intervention with only 6% (3/49) of patients needing to review parts of the video due to challenges in their environment. It should be noted, however, that the study nurse had an important role in providing non-directive support monitoring subtle changes in patient health status to adjust pacing or timing accordingly as well as giving further clarification and accommodating to fluctuating levels of decisional capacity.

Finally, the IP-SDM does not explicitly address decisional capacity. This may be an important concern for healthcare professionals working with patients and families facing serious advanced illness, or where the patient/family member has unique challenges to involvement in decision-making (i.e., developmental stage, cognitive or sensory barriers) that require special attention during shared decision-making. It remains to be seen at which stages assessment and intervention are needed. Overall, the IP-SDM and the connection of the CPR-VDA to each step in the model showed good face validity and contributed to better understanding the decision-making process with patients and professionals in a renal health setting. Further work is necessary to integrate the concept of decisional capacity explicitly in the IP-SDM.

4.1.2 Nurses' Roles in Interprofessional Practice

The nephrology physicians attended rounds routinely with each patient during treatments with an interdisciplinary team that often included the nurse, clinical coordinator, pharmacist, social worker, and family member when available. It should be noted, however, that the interdisciplinary team was in the vicinity during the physician discussion with the patient and family about the CPR decision post intervention but had no formal role. Although the entire team was briefed about the study and goals, there were no structured learning opportunities provided for nursing staff to learn more about how to support decision-making or how to integrate

decision aids in their clinical practice. In previous studies, provider focused strategies such as educational materials and meetings (in-person or online), skills workshops, educational outreach and audit and feedback, have been combined with patient focused strategies (patient decision aids, patient activation) with variable effect to improve implementation of shared decision-making by members of the interprofessional healthcare team (Légaré et al., 2014).

In preparation for shared decision-making research, the author reviewed the Ottawa Decision Support Tutorial (www.decisionaid.ohri.ca/ODST/), an online tutorial provided free of charge by the Ottawa Hospital Research Institute. As study nurse, the author took on the role of decision coach during the study process by helping patients navigate the CPR decision worksheet and video due to vascular access in their arm, poor lighting, positioning for treatment, and fatigue. The author clarified when necessary and employed therapeutic communication skills throughout the interview. During the process of being with participants during the intervention and especially while completing the values clarification worksheet, the author was an empathetic listener and formed a therapeutic relationship. Physicians reinforced the work of the study nurse and the CPR-VDA intervention during their discussion with the patient after the intervention. Thus, the study nurse as decision coach had an explicit and formal role on the interprofessional team regarding decision-making. Optimizing the decision-making environment to increase the patients' ability to engage meaningfully in decision-making is a clear role for the study nurse providing decision support in this study, however, the study nurse was not part of the clinical team and dialysis nurses may need additional preparation or release time to take on this additional role within their scope of practice. Nurses have a clear ethical and professional obligation to support healthcare decision-making (Canadian Nurses Association, 2008) and nurses from within the dialysis team could potentially become more adept at decision coaching to offer additional support to patients who are involved in CPR and other treatment discussions. Other team members such as social workers, clinical psychologists, spiritual care workers, hospital volunteers, etc. could also integrate the decision-coaching role. Further work is needed to include patient decision support and outline interprofessional roles explicitly in the organization of care, or care pathway for patients with ESRD.

4.1.3 Supporting health care delivery

Key in understanding healthcare delivery is appreciating the organizational and social structures that influence practice. Changing the organization of care was beyond the scope of the

study. However, it is useful to think about how such structures might support improved decision-making. First, the CPR-VDA is an explicitly listed tool in local health region policy (Saskatoon Health Region, 2015), including a link to the CPR-VDA and a printed brochure adapted from the video. The health region could consider supports for education or instruction on how to implement the decision aid into practice. The policy does identify that resuscitation care plans in acute care facilities that include that the CPR decision must be discussed within 24 hours of admission using a shared decision-making process by the most responsible physician or designate (a professional member of the health care team with knowledge of resuscitation and the patient's medical history). Opportunities for formal training to improve the skills needed to facilitate shared decision-making are needed. In this study, 18 out of 50 hemodialysis patient charts reviewed had no resuscitation care plan – therefore healthcare providers would use CPR and other resuscitative measure if needed. Future quality improvement work could be undertaken to improve the documentation of the CPR decision.

Second, organizations such as the Canadian Medical Association (2004) and Canadian Nurses Association (2008), as well as the Canadian Interprofessional Health Collaborative (2010) already support shared decision-making practice in Canada. Evidence on shared decision-making and interprofessional healthcare practice is growing, demonstrating a collaborative healthcare workforce that optimizes the skills of each profession and shares the management and delivery of services can strengthen fragmented systems and ultimately improve health outcomes (World Health Organization, 2010). Purposeful collaborative care can prevent adverse events and patient harm, decrease waste and cost, increase coordination of care and services, and improve retention and recruitment through increased job satisfaction (Mitchell et al., 2012). Mulley, Trimble, and Elwyn (2012) argue that implementing treatments that patients do not want, or even without assessing their preferences, leads to a medical error due to "preference misdiagnosis" causing iatrogenic harm to patients. The need for effective shared decision-making is within each healthcare professional's scope of practice, supported by legislation, policy, and research. The reflection on interprofessional roles and organizational structures also reinforces the face validity of the IP-SDM. More work is needed to see these organizational and social structures be realized in current healthcare practice.

4.1.4 Implications for research

The *decisional capacity* concept analysis highlighted gaps in the literature about roles of the interdisciplinary healthcare team and both the ethical obligation and key assessments performed by nurses. The lack of feasible standardized tools to measure the concept may also make research and determinations of decisional capacity in practice challenging. Further exploration is needed to fully understand how many elements of decisional capacity are needed to satisfy a threshold for having capacity. As well, more research is needed with people who are vulnerable to poor involvement in decision-making (i.e., people with lower literacy, with mental health and addictions challenges, with developmental delay, or the very young and the very old). Research on a capabilities approach that reflects a commitment to engage the patient in health care decisions at their level could improve care (Entwistle & Watt, 2013). Consistent with the nursing role, excellent dialogue may be facilitated by opening space for communication and building relationships with people on their own terms. Treating patients as persons who have capabilities to participate in decision-making is important even when they may not meet the definition of full decisional capacity. For example, work done on capacity-adjusted shared decision-making approaches, where decisions are placed in context, family and support persons take on a larger role in clinical encounters shows great promise, ensuring decision aids are taken home and reviewed with family before consultation appointments (Ho et al., 2015).

In the CPR-VDA study, 11 out of 49 patients identified as other than Caucasian. However, we did not change our general approach or tool to account for other specific cultures. It is not known whether this is needed or whether it would improve communication quality. A culturally adapted version of the values clarification sheet (based on the Ottawa Personal Decision Guide) was shown to better meet the needs of Aboriginal women when used with decision coaching (Jull, Giles, Boyer, & Stacey, 2015; O'Connor, Stacey, & Jacobsen, 2015). A (randomized) control group could further strengthen the study design to determine the effectiveness of the CPR-VDA intervention. Here, the CPR-VDA was not compared to usual practice or to a control group and therefore participants were not randomized to the intervention; thus we cannot be certain that the intervention alone caused the change in outcomes. In future, a pragmatic trial designed to test the CPR-VDA in real life situations using different settings and diverse populations could help test the clinical applicability of the decision aid.

4.1.5 Implications for Education

Healthcare professionals need more support to integrate a shared decision-making approach in their practice. Our study highlighted healthcare providers had variable skills in involving patients during post intervention meetings (average score = 25.66/48, range 9-47, standard deviation 7.41). This is consistent with findings from a systematic review of studies using the OPTION instrument that also described low levels of primary care patients being involved in decision-making or care being adjusted to patient preferences (Couët et al., 2015). Although a current Cochrane review of interventions for improving the adoption of shared decision-making showed no singularly best intervention, there was evidence to suggest that interventions targeting patients and /or healthcare professionals are better than no intervention (Légaré et al., 2014).

Interprofessional education and collaboration are important issues in healthcare education, delivery, research, and policy (Canadian Interprofessional Health Collaborative, 2010). Purposeful collaborative care teams including patients, families, and interdisciplinary healthcare team members can prevent adverse events and patient harm, decrease waste and cost, increase coordination of care and services, and improve patient-centered care delivery (Mitchell et al., 2012). In order to provide a collaborative ready workforce, universities across Canada have been trialing different methods of delivering interprofessional education experiences to undergraduate health science students with varying degrees of success. Shared decision-making is most successful when experienced and expert healthcare professionals use teamwork and collaborative practices. In a qualitative study that looked at communication on a general internal medicine ward at two large urban Canadian hospitals, teamwork in the practice setting was challenging and interprofessional discussions rare (Zwarenstein, Rice, Gotlib-Conn, Kenaszchuk, & Reeves, 2013). This research validates this author's experiences within clinical and practice areas in acute care hospitals. Supporting education initiatives with experienced healthcare providers to improve collaborative practice and shared decision-making may improve communication and decision-making with patients and families and ultimately facilitate patient centered care.

Table 7 Impacts on Theory and Nursing

Impacts on Theory and Nursing	
Theory	IP-SDM can be used to facilitate definitive roles for nurses in the shared decision-making process and can guide practitioners to collaborate with all stakeholders when important healthcare conversations need to be held.
Interprofessional Practice	New awareness of the importance of collaborative work with the healthcare team and patients and family. Move away from traditional patient / doctor dyad to include a larger support team with members of the healthcare team when appropriate inclusive of the patient and family team.
Healthcare Organizations	Needs to be supportive of research, move to cross-site research to improve participation, implement polity to use clinically relevant research where positive results are observed. Create policy, remove roadblocks.
Social Structures	Scope of practice and legal consent laws are consistent with shared decision-making approach.
Research	Works best when it is a collaborative effort and has high stakeholder engagement at all stages. Need financial and organizational supports to innovate and conduct research.
Education	Workshops and events are needed to explain and practice using the decision aid in the clinical setting. Use of decision aids is not common practice for all healthcare providers, an integrated approach is needed to train healthcare teams in the development and use of patient decision aids.

4.2 Limitations

The CPR-VDA study employed a small number of participants, which limits generalization of results to other populations. Although dyads of patient and family member were sought, it was not feasible upon implementation. In a study of this nature, with seriously ill patients, question fatigue can be a concern. Future studies with this patient population may wish to utilize video or audio recordings to limit fatigue in answering the questions and eliminate the need of the study nurse manually recording answers during the interview. The study design is a general limitation, as with most quasi-experimental designs. The research questions could be approached through a randomized control trial (RCT) design to determine the effectiveness of the CPR-VDA intervention. This is, however, not practical for a master's thesis on a limited timeframe, as an RCT would require more participants. Here, the CPR-VDA was not compared to usual practice or to a control group and did not randomize the selection of the subjects. While

there are limitations, this study still provides valid and reliable information on which to improve practice, policy, and future research efforts.

4.3 Conclusion

Improved communication with ESRD patients is a high priority target for improving end-of-life care. Conversations about CPR occurred for every patient in our study. These conversations are necessary to ensure healthcare providers are following the wishes of patients and families in the event of a cardiac or respiratory arrest. Patients with ESRD face many challenging healthcare decisions, often have fluctuating cognitive impairments while receiving long-term hemodialysis, and have a high rate of comorbid conditions including heart disease resulting in high mortality rates. However, they are capable to participate in healthcare decision-making, especially with support of targeted low literacy tools like the CPR-VDA and decision coaching from an advanced practice nurse. Patients and families can be increasingly informed about complex healthcare decisions like CPR and can share their values and preferences with healthcare professionals with the right supports. This study demonstrates that the novel video decision aid (CPR-VDA) shows good efficacy and is feasible to use in a busy dialysis clinic. Nurses can contribute to healthcare improvements beyond their nursing practice and clinical expertise, providing leadership by analyzing and further developing healthcare theory and research in order to advance nursing knowledge and improve population health.

4.4 References

Beattie, E. (2009). Research Participation of Individuals with Dementia: Decisional Capacity, Informed Consent, and Considerations for Nurse Investigators. *Research in Gerontological Nursing, 2*(2), 94-102.

Canadian Interprofessional Health Collaborative. (2010). A National Interprofessional Competency Framework. In University of British Columbia (Ed.). Vancouver, BC.

Canadian Medical Association. (2004). CMA Code of Ethics. Available: www.cma.ca/Assets/assets-library/document/en/advocacy/policy-research/CMA_Policy_Code_of_ethics_of_the_Canadian_Medical_Association_Update_2004_PD04-06-e.pdf

Canadian Nurses Association. (2008). *Code of Ethics for Registered Nurses*. Ottawa, ON.

Carroll, D. W. (2010). Assessment of Capacity for Medical Decision Making. *Journal of Gerontological Nursing, 36*(5), 47-52. doi:10.3928/00989134-20100303-03

Charland, L. C. (2015). Decision-Making Capacity. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy*.

Couët, N., Desroches, S., Robitaille, H., Vaillancourt, H., Leblanc, A., Turcotte, S., . . . Légaré, F. (2015). Assessments of the extent to which health- care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expectations, 18*(4), 542-561. doi:10.1111/hex.12054

Entwistle, V., & Watt, I. (2013). Treating Patients as Persons: A Capabilities Approach to Support Delivery of Person-Centered Care. *The American Journal of Bioethics, 13*(8), 29-39. doi:10.1080/15265161.2013.802060

Grisso, T., & Appelbaum, P. S. (1998). *Assessing competence to consent to treatment : a guide for physicians and other health professionals*. New York: Oxford University Press.

Ho, A., Pinney, S. J., & Bozic, K. (2015). Ethical Concerns in Caring for Elderly Patients with Cognitive Limitations: A Capacity- Adjusted Shared Decision- Making Approach: A Capacity- Adjusted Shared Decision- Making Approach. *Journal of Bone and Joint Surgery, 97*(3), e16(11)-e16(16). doi:10.1016/S0021-9355(15)74555-8

Jull, J., Giles, A., Boyer, Y., & Stacey, D. (2015). Cultural adaptation of a shared decision making tool with Aboriginal women: a qualitative study. *BMC Medical Informatics and Decision Making, 15*, 1.

Kolva, E., Rosenfeld, B., Brescia, R., & Comfort, C. (2014). Assessing decision-making capacity at end of life. *General Hospital Psychiatry, 36*(4), 392-397. doi:10.1016/j.genhosppsych.2014.02.013

Légaré, F., Stacey, D., Turcotte, S., Cossi, M.-J., Kryworuchko, J., Graham, I. D., . . . Donner-Banzhoff, N. (2014). Interventions for improving the adoption of shared decision making by healthcare professionals. *The Cochrane Database of Systematic Reviews,* 9, CD006732. doi:10.1002/14651858.CD006732.pub3

Mitchell, P., Wynia, M., Golden, R., McNellis, B., Okun, S., Webb, C. E., . . . Von Kohorn, I. (2012). Core principles & values of effective team-based health care. *Institute of Medicine*, 32. doi:http://www.iom.edu/tbc

Mulley, A. G., Trimble, C., & Elwyn, G. (2012). Stop the silent misdiagnosis: patients' preferences matter. *The BMJ, 345*(nov07 6). doi:10.1136/bmj.e6572

O'Connor, A., Stacey, D., & Jacobsen, A. (2015). Ottawa Personal Decision Guide. Available: www.decisionaid.ohri.ca/docs/das/OPDG.pdf

Owen, G. S., Szmukler, G., Richardson, G., David, A. S., Raymont, V., Freyenhagen, F., . . . Hotopf, M. (2013). Decision-making capacity for treatment in psychiatric and medical in-patients: cross-sectional, comparative study. *The British Journal of Psychiatry, 203*(6), 461-467. doi:10.1192/bjp.bp.112.123976

Saskatoon Health Region. (2015). Resuscitation Policy. Available: www.saskatoonhealthregion.ca/about/RWPolicies/7311-60-016.pdf

Sessums, L. L., Zembrzuska, H., & Jackson, J. L. (2011). Does this patient have medical decision-making capacity?(Clinical report). *JAMA, 306*(4), 420.

Seyfried, L., Ryan, K. A., & Kim, S. Y. H. (2012). Assessment of Decision-Making Capacity: Views and Experiences of Consultation Psychiatrists. *Psychosomatics*. doi:10.1016/j.psym.2012.08.001

Simpson, C. (2010). Decision-making capacity and informed consent to participate in research by cognitively impaired individuals. *Applied Nursing Research, 23*(4), 221-226. doi:http://dx.doi.org/10.1016/j.apnr.2008.09.002

Taylor, D., Masse, L., Ho, A., Rekart, M. L., Tyndall, M., Henry, B., . . . Buxton, J. (2013). A brief tool to assess capacity to consent for medical care among homeless individuals with

problematic substance use: study protocol. *Archives of public health = Archives belges de santé publique, 71*(1), 11. doi:10.1186/0778-7367-71-11

Tunzi, M. (2001). Can the patient decide? Evaluating patient capacity in practice. *American Family Physician, 64*(2), 299.

World Health Organization. (2010). Framework for Action on Interprofessional Education & Collaborative Practice.

Zwarenstein, M., Rice, K., Gotlib-Conn, L., Kenaszchuk, C., & Reeves, S. (2013). Disengaged: a qualitative study of communication and collaboration between physicians and other professions on general internal medicine wards. *BMC Health Services Research, 13*. doi:10.1186/1472-6963-13-494